

A Novel, Mental-Imagery Based, Psychological
Intervention for Anxiety in People with Mild to
Moderate Intellectual Disability: Co-Development
and Initial Testing

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for the Degree of Doctor of Philosophy

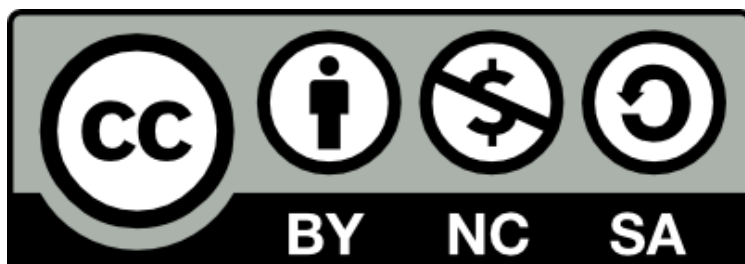
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Abstract¹

Background: People with intellectual disabilities experience anxiety disorders at a higher rate than the general population. However, there is a lack of evidence-based accessible interventions for this population. Mental imagery-based interventions are used to treat anxiety disorders within the general population but have not been systematically explored within this client group.

Aims: This project's aims included: (1) To synthesise the literature about the abilities of people with intellectual disabilities to engage with mental imagery (the generation, maintenance, inspection, and transformation of mental images), and the role of mental imagery within existing psychological interventions for this population (Study 1); (2) To review and synthesise the literature around inclusive research in health and social care with people with intellectual disabilities, to synthesise the roles co-researchers play in such research, and capture their experiences of engaging in inclusive research (Study 2); (3) To explore the phenomenology of mental imagery in people with intellectual disabilities, in order to understand what factors facilitate or hinder the development and use of mental imagery in this population, and to consider the implications of these in terms of developing a psychological intervention (Study 3); (4) To co-develop an anxiety intervention using a mental imagery approach for people with mild to moderate intellectual disabilities (Study 4); (5) To conduct initial testing and refinement of the intervention in NHS settings, and to assess acceptability (Study 5).

Method: A mixed methods approach was used including systematic reviews of the literature (Study 1 and 2). A qualitative study was conducted and results from both verbal interviews, and creating an image using collage and drawing, were analysed and synthesised using Interpretative Phenomenological Analysis (Study 3). The framework of Experience Based Co-Design was adapted to co-develop the psychological intervention (called Co-MAID) alongside

¹ Appendix 1 contains an infographic summary of this research project

stakeholders and people with intellectual disabilities. This process was evaluated using semi structured interviews and analysed using Template Analysis (Study 4). Initial testing of the intervention was conducted with six participants recruited from NHS clinical services. This was evaluated using Single Case Experimental Design and semi structured interviews were conducted with participants and their supporters to assess the acceptability of the intervention (Study 5).

Results: Study 1 systematically reviewed 41 papers of variable quality and designs, finding that people with intellectual disabilities can engage with mental imagery, with appropriate adaptations. Facilitators and barriers to using mental imagery were identified. Study 2 synthesised 17 papers covering a diverse range of health and social care topics. People with intellectual disabilities were involved across multiple methodologies and research tasks. Study 3 analysed qualitative verbal and visual data using Interpretative Phenomenological Analysis to demonstrate that people with intellectual disabilities experience rich, detailed mental images across all sensory modalities. Study 4 employed Experience Based Co-Design to identify and implement numerous intervention adaptations, improving the accessibility and acceptability of the intervention. Participants engaged fully with EBCD, finding it enjoyable and valuable. Study 5 reported results of initial testing in NHS services, with good adherence (five participants completed the intervention with 92.6% session attendance). Template analysis revealed positive experiences with participants reporting improved mood. Three participants (50%) demonstrated reliable change on the primary anxiety measure, meeting clinically significant change criteria.

Conclusion: People with intellectual disabilities can engage with mental imagery interventions and work as co-researchers to develop psychological interventions. Further research with larger samples and controlled designs is required to establish the feasibility of a randomised control trial leading to a Phase III trial.

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Abbreviations

AMED	Allied and Complementary Medicine Database
BNI	British Nursing Index
CBT	Cognitive Behavioural Therapy
CFT	Compassion Focused Therapy
CINAHL	Cumulative Index to Nursing and Allied Health Literature
Co-MAID	Co-Designed Mental Imagery intervention for Anxiety in people with mild to moderate Intellectual Disabilities
CRedit	Contributor Roles Taxonomy
DSM	Diagnostic and Statistical Manual of Mental Disorders
EBCD	Experience-Based Co-Design
EMBASE	Excerpta Medica database
EMDR	Eye Movement Desensitisation and Reprocessing
EThOS	Electronic Theses Online Service database
FRAME	Framework for Reporting Adaptations and Modifications-Expanded
FSIQ	Full Scale Intelligence Quotient
HAP	Health Action Plan
HDAS	Healthcare Databases Advanced Search
ICD	International Classification of Diseases
ID	Intellectual Disability
IPA	Interpretative Phenomenological Analysis
IQ	Intelligence Quotient
MeSH	Medical Subject Headings
MI	Mental Imagery
MIQ-ID	Mental Imagery Questionnaire for People with Intellectual Disability
MRC	Medical Research Council
NHS	National Health Service
NIHR	National Institute for Health and Care Research
PPI	Public and Patient Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
RfPB	Research for Patient Benefit
SCED	Single Case Experimental Design
SCRIBE	Single-Case Reporting guideline In Behavioural interventions
STAR group	Sharing Thoughts About Research Group
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

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Publications and presentations

Published papers resulting directly from this doctoral research:

Hewitt, O. M., Steel, C., Hales, S. A., Hayden, N., Gundeslioglu, H., Tapp, K., & Langdon,

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mental imagery in people with intellectual disabilities. *Psychology and Psychotherapy: Theory, Research and Practice*, 96(1), 25-39.

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Develop a Novel Psychological Intervention With People With Intellectual Disabilities and Stakeholders. *Journal of Applied Research in Intellectual Disabilities*, 38(1), e70022.

Papers under review resulting directly from this doctoral research:

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novel, mental imagery-based anxiety intervention for people with mild to moderate intellectual disabilities using single case experimental design

Papers in preparation resulting directly from this doctoral research:

Hewitt, O.M., Larkin, M. & Langdon, P.E. (in preparation). The use of creative methodologies to disseminate research findings: Experiences of co-researchers with intellectual disabilities.

Hewitt, O.M., Steel, C., Thompson, P.A., & Langdon, P.E. (in preparation) The Mental Imagery Questionnaire for People with Intellectual Disabilities (MIQ-ID): development and validation

Conference presentations resulting directly from this doctoral research:

Hewitt, O (2023, 7-8 December) Improving anxiety in people with mild to moderate intellectual disability: Developing and testing a novel, co-produced, mental imagery intervention. 20th Seattle Club conference, University of Birmingham.

Hewitt, O. (2024, 23-26 July) Co-MAID: Co-designing a novel, mental imagery-based intervention for anxiety in people with intellectual disabilities. 52nd annual conference of British Association for Behavioural and Cognitive Psychotherapies, Manchester, UK

Hewitt, O. (2024, 5-8 August) Co-MAID: Co-designing a novel, mental imagery-based intervention for anxiety in people with intellectual disabilities. International Association for the Scientific Study of Intellectual and Developmental Disabilities. 17th world congress, Chicago, USA

Hewitt, O. (2024, 12-13 December) Co-maid: co-designing a novel, mental imagery-based intervention for anxiety in people with intellectual disabilities. 21st Seattle Club conference, Kings College London

Hewitt, O. (2025, 3-6 September) Mental imagery and psychological therapy in people with intellectual disabilities 53rd annual conference of British Association for Behavioural and Cognitive Psychotherapies, Glasgow, UK

Chapter 1 – General Introduction

This chapter introduces and sets the context for the wider research project being presented for examination. I initially describe the clinical population (that of people with intellectual disabilities) on which the research is focused. I outline the increased rates of mental health disorders, and the lack of evidence-based interventions available for this group. I then describe risk factors associated with people with intellectual disabilities and the development and maintenance of anxiety disorders and problems. Next, I consider psychological interventions for anxiety within this population, both in terms of the theoretical underpinnings of such interventions, and what adaptations are required to make them accessible for people with intellectual disabilities. The role of mental imagery in the development, maintenance and treatment of anxiety is summarised, and a rationale for focusing on mental imagery interventions when treating anxiety in people with intellectual disabilities is described. I outline the development and adaptation of complex psychological interventions and describe the use of inclusive research methods within this project. I then set out my epistemological stance and describe how this has shaped the research project. Finally, I outline the subsequent chapters, and the overarching aims of the thesis.

1.1 Intellectual Disability: Definitions and Prevalence

The International Classification of Diseases, 11th edition (ICD-11) describes intellectual disability as a ‘group of etiologically diverse conditions’ characterised by significant impairments in intellectual functioning and adaptive behaviour, occurring during the developmental period and being categorised into the following classifications based on standardised assessments: mild, moderate, severe, and

profound (World Health Organization, 2019). Such impairments are approximately two or more standard deviations below the mean (less than the 2.3rd percentile), based on appropriately normed, individually administered standardized tests.

Similarly, the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) define intellectual disability as beginning in childhood and comprising deficits in intellectual functioning confirmed by clinical evaluation and standard IQ testing, alongside deficits in adaptive functioning that hamper conforming to developmental and sociocultural standards.

Based on global data from 1990-2019, Nair et al. (2022) report that in 2019, there were 107.62 million (1.74%) individuals with intellectual disability. Highest prevalence rates were found in low to middle socio demographic regions, and the relative inequalities between low and high socio demographic regions has increased over the last three decades.

1.2 The Development and Maintenance of Anxiety Disorders and Problems in People with Intellectual Disabilities

People with intellectual disabilities experience higher rates of mental health disorders and problems² than the general population (Shehan et al., 2015; Buckley et al., 2020). This includes rates of anxiety disorders and problems (Edwards et al., 2022). Various factors contribute to the development and maintenance of anxiety disorders and problems in people with intellectual disabilities. Some of these are shared with the

² Within this thesis the term ‘mental health disorders and problems’ will be used for consistency by the author, except when referencing other research studies which use alternative terms. The term ‘mental health disorder’ refers to a condition that meets certain diagnostic criteria, whilst a ‘mental health problem’ describes difficulties that may not meet such criteria. Within the wider literature various terms are used including psychological disorder, psychiatric disorder, mental disorder, mental health difficulty, psychopathology etc

general population (such as poor social support and unemployment; Ailey, 2008), whilst others are specific to people with intellectual disabilities (such as cognitive limitations, impaired communication skills, and poor coping skills; Hsieh, 2020). Anxiety disorders have a significant impact on the quality of life for people with intellectual disabilities and without treatment, they tend to persist over time, becoming chronic and difficult to treat (Groves et al., 2022).

Risk Factors Associated with the Development and Maintenance of Anxiety Disorders and Problems

Risk factors that have been explored in the development and maintenance of anxiety disorders and problems in people with intellectual disabilities include health-related factors, psychosocial factors and demographic factors.

Health Related Factors

Genetic Syndromes

Some genetic conditions are associated with intellectual disabilities and higher rates of anxiety disorders and problems. Individuals with Williams Syndrome are at higher risk of experiencing an anxiety disorder (48 %) compared to the general population (4%) and other individuals with intellectual disability (Edwards et al., 2022). Specific types of anxiety disorders are associated with some syndromes, for example social anxiety and specific phobias being most common in fragile X and 22q11.2 deletion syndromes (Bertrán et al., 2018, Gabis et al., 2011, Jolin et al., 2012).

Comorbid Conditions

People with intellectual disabilities experience higher rates of various comorbid conditions such as autism (Appleton et al., 2019), epilepsy (Deb, 2000) and attention-deficit/hyperactivity disorder (ADHD; Al-Khudairi et al., 2019).

Both children and young adults with Autism Spectrum Disorder (ASD) experience high rates of co-occurring anxiety disorders, with prevalence between 42% (Bradley et al., 2004) and 80% (Simonoff et al., 2008). For people with ASD, it is relatively common to have an intellectual disability, with rates of 37% being reported (Rivard et al., 2015).

Whilst higher rates of anxiety are seen in people with intellectual disabilities and epilepsy (compared to people with intellectual disability and no epilepsy) the heterogeneous nature of this group make patterns of presentations hard to define (Brizard et al., 2021).

Several studies have shown a higher prevalence of ADHD in adults with intellectual disability ranging from 8.7% to 20.4% (Cantwell, 1996). Adults with ADHD and intellectual disabilities present with higher rates of anxiety and are at risk of being inappropriately medicated (Al-Khudairi et al., 2019).

Anxiety disorders in people with intellectual disabilities often co-occur with other mental health conditions, including depression (Hermans & Evenhuis, 2013), which may make understanding the presentation of an anxiety disorder difficult.

Chronic health conditions and specifically hearing impairments are also associated with anxiety in people with intellectual disabilities (Hsieh, 2020).

Cognitive, Social, and Communicative Impairments

People with intellectual disabilities may struggle to understand and cope with everyday situations, leading to increased levels of stress and anxiety. Individuals with intellectual disabilities have unique cognitive profiles. Understanding the role of each person's particular strengths and difficulties is essential when making sense of how mental health disorders and problems have developed, been maintained and could

potentially be more successfully addressed for that individual (commonly done through formulation within clinical settings). However, there are several key areas of cognitive skills in which people with intellectual disabilities frequently display limitations. These include attention, working memory, learning and memory, executive functions and language and reading (Hronis et al., 2017). These cognitive deficits may contribute to increased vulnerability to developing and sustaining mental health disorders and problems through various mechanisms, for example poor executive functioning being associated with cognitive rigidity and the development mental health disorders and problems (Reid et al., 2024).

Individuals with intellectual disabilities may struggle with understanding and responding to social cues, managing emotions, and problem-solving, all of which can contribute to anxiety. Poor adaptive functioning may result in them experiencing challenges across social, conceptual, and practical domains. Their lower cognitive abilities and adaptive skills can make it harder to cope with everyday challenges, leading to increased perceived stress and anxiety (Powers et al., 2024). However, whilst such associations may resonate with clinical impressions of this population, there remains a lack of robust studies into such associations.

Psychosocial Factors

Intrapersonal psychological factors associated with anxiety disorders and problems include shame, and low self-esteem. Shame can contribute to social withdrawal and exclusion, and the development of poor psychological health and anxiety in people with intellectual disabilities (Marriott et al., 2020). Experiencing stigma, exclusion and discrimination can negatively impact self-esteem, and contribute

to reduced levels of social support, increasing susceptibility to anxiety (Scior & Werner, 2016).

Interpersonal factors include attachment difficulties, bullying, stigma, and a lack of social support. People with intellectual disabilities are at increased risk of attachment difficulties (Hamadi & Fletcher, 2021), including higher levels of insecure attachments with primary caregivers. This has implications for their relationships with those providing informal and paid support and can result in difficulties developing self-compassion (Cooper & Frearson, 2017).

Stressful life events have been the most well researched area regarding psychosocial risk factors for mental health disorders in people with intellectual disabilities. The term “stressful life events” describes a range of events such as change in employment or residence, or the death of a loved one (Hsieh et al., 2020). Several correlational and prospective studies indicate that, for people with intellectual disabilities, both the degree of stress and amount of stressful life events are associated with increased psychopathology (Esbensen & Benson, 2006; Hove & Havik, 2010; Hulbert-Williams et al., 2011; Hulbert-Williams et al., 2014; Owen et al., 2004; Scott & Havercamp, 2014). Life events were associated with anxiety in young adults with intellectual disabilities (Espie et al., 2003).

A range of traumatic events (e.g. sexual abuse, political violence) are associated with increased mental health disorders including anxiety disorders (McNally et al., 2021) such as Post Traumatic Stress Disorder (Catani & Sossalla, 2015) and Obsessive–Compulsive Disorder (Stavrakaki & Antochi, 2004).

Social support and social contacts protect against anxiety disorders and problems in older people with intellectual disabilities (Hermans & Evenhuis, 2013), with loneliness associated with increased levels of anxiety (Bond et al., 2020).

Demographic Factors

Various demographic factors have been associated with higher rates of anxiety in people with intellectual disabilities such as older age (Hsieh, 2020). Women with intellectual disabilities report higher rates of anxiety than men, in line with the general population (Chester et al., 2013; Cooper et al., 2016). Whilst people of all ages with intellectual disability from a South Asian background have lower levels of using mental health services in the UK (Durà-Vilà & Hodes, 2012), it is unclear whether they experience lower levels of mental health disorders and problems, or whether additional factors such as stigma act as barriers to accessing such services.

Several studies have reported that severity of level of intellectual disability affects prevalence rates of anxiety. Whilst some studies report individuals with severe intellectual disabilities experience lower rates of anxiety than those with moderate or mild intellectual disability (Hermans & Evenhuis, 2013; Holden & Gitlesen, 2004), others suggest adults with severe intellectual disabilities show higher levels of anxiety than those with mild, moderate or profound intellectual disabilities (Hove & Havik, 2010). However, it is difficult to understand if this reflects an actual lowering of anxiety rates in this subgroup or reflects increased difficulties in assessing and diagnosing anxiety due to increased communication difficulties and a lack of reliable and valid measures (Hermans et al., 2011).

In addition to this range of risk and maintenance factors, there are several issues around identifying anxiety and accessing appropriate interventions for this population.

Cognitive and communication difficulties can impair an individual's ability to understand the psychological distress they are experiencing and communicate this to other people. A lack of meaningful day activities may inadvertently mean that people are not exposed to various everyday situations which may relate to objects of fear (e.g. social anxiety), meaning such difficulties remain hidden. Diagnostic overshadowing may mean that clinicians attribute symptoms of anxiety to the intellectual disability, rather than identifying it as a mental health disorder or problem that requires treatment. Difficulties in accessing specialist services for the assessment and treatment of anxiety disorders in this population may mean anxiety disorders or problems are not identified promptly and appropriately treated. This may result in people being inappropriately medicated due to a lack of evidence based psychological intervention (Gomez et al., 2021). There are also few appropriately validated clinical measures to assess anxiety in this population and capture changes over time in symptoms, although new tools are being developed (e.g. Mingins et al., 2024). People with intellectual disabilities largely rely on other people to make and access medical appointments. Reliance on others to access psychological support (both assessment and attending therapy sessions).

Such myriad factors contribute to higher rates of mental health disorders and problems for people with intellectual disabilities and have implications for their treatment, including through psychological interventions.

1.3 Psychological Interventions for Anxiety Disorders and Problems in People with Intellectual Disabilities

Clinicians lack robust, evidence-based, psychological interventions to offer people with intellectual disabilities who are struggling with anxiety. This results from a variety of reasons. Historically, clinicians assumed people with intellectual disabilities

were unable to access psychological interventions. Talking therapy, or interventions including cognitive components were thought to be inaccessible, due to the cognitive limitations of people with intellectual disabilities (Fynn et al., 2023), and therapeutic disdain (an incorrect prejudice that assumes people with intellectual disabilities are unable to benefit from psychological therapies) from mental health professionals (Langdon, 2020). Instead, individuals were treated through medication and behaviour modification (Whitehouse et al., 2006). However, it is increasingly recognised that those with cognitive limitations, including intellectual disabilities can benefit from a range of psychological approaches (e.g. cognitive behavioural therapy; Taylor et al., 2008).

Various psychological interventions have been evaluated with people with intellectual disabilities across a range of psychological disorders and problems. Examples include Cognitive Behavioural Therapy (CBT) for anxiety (Giannaki & Hewitt, 2021; Roberts & Kwan, 2018), anger (McWilliams et al., 2014; Wilner et al., 2013a), and depression (Hartley et al., 2015; Jahoda et al., 2006), and psychodynamic interventions for interpersonal difficulties and sexual offending (MacDonald et al., 2010) and anxiety, anger and offending behaviours (Newman & Beail, 2010). However, the current evidence base largely consists of small studies which are heterogeneous in nature, making conclusions about their efficacy and effectiveness difficult to draw (Cameron et al., 2021). Some interventions focus on delivering psychological interventions to family members of carers rather than to the person with intellectual disability directly (or in conjunction with a supporter) (Surley et al., 2024). CBT interventions are difficult for people with more severe intellectual disabilities to access (e.g. Fynn et al., 2023). There are many barriers to conducting the large, multi-site, randomised controlled trials that needed to provide definitive evidence for an intervention in this population. These

include a people with intellectual disabilities comprising a relatively small proportion of the population, concerns about ethical issues (such as capacity and consent), pressures on clinical services leading to a lack of capacity to engage in research and gatekeeping by clinicians and others (see Langdon et al., 2025 for a discussion of these issues).

Theoretical Underpinnings of Psychological Interventions and the Resulting Interventions

Within the treatment of psychological disorders and problems in the general population, there are several broad schools of psychological theories regarding the cause and development of anxiety disorders and problems (and the resulting interventions based on such theories). Such ideas include behavioural, cognitive behavioural, third wave, and psychodynamic theories. In the next section I will summarise theories around the development and maintenance of anxiety from each of these schools. The resultant interventions are then described, illustrating how these have been derived from the psychological theory.

Behavioural Theories around the Development and Maintenance of Anxiety Disorders and Problems

Behavioural theories propose that observable behaviours are acquired through a process of associating stimuli with responses (Zinbarg et al., 2022). Learning theorists suggest several ways in which anxiety can be learned (develop). Two-factor theory in learning (Mowrer, 1960), specifically in the context of avoidance behaviour, proposes that learning occurs through two intertwined processes: classical conditioning (stimulus learning) and operant conditioning (response learning). A neutral stimulus can become associated with a negative or aversive experience, leading to a conditioned fear response (classical conditioning). Anxiety disorders can be maintained through

operant conditioning, in which avoidance plays a key role. As the individual avoids the feared situation or object, the immediate reduction in their anxiety negatively reinforces the avoidance behaviour. However, this prevents the fear response reaching extinction, thus maintaining the anxiety over the longer term.

Behavioural Interventions for Anxiety Disorders and Problems

Various behavioural interventions have been developed for anxiety disorders and problems based on learning theories. Interventions may address the classically conditioned fear response and aim to replace this with a different response (such as relaxation). This may be done through exposing the individual to the feared stimuli in a range of ways such as systematic desensitization (progressively moving a participant through a hierarchy that gradually exposes them to the feared stimulus, whilst in a relaxed state) and stimulus fading (gradually modifying characteristics of a stimulus). Avoidance of feared stimuli is also addressed through graded exposure. Exposure to the feared stimulus results in a reduction in anxiety through the mechanisms of habituation (the gradual decrease in a person's fear response to a feared stimulus as they are repeatedly exposed to it) and extinction (inhibitory learning, whereby a learned response is weakened when a conditioned stimulus is no longer paired with an unconditioned stimulus). A relaxed state may be taught through interventions such as progressive muscle relaxation.

Rosen et al. (2016) completed a systematic review that included seven studies using single case experimental designs and behavioural interventions to address anxiety in autistic people with moderate or severe intellectual disabilities. They concluded that behavioural interventions, and desensitization and reinforcement procedures specifically, are efficacious in this client group.

Alongside people with autism and intellectual disability Langdon et al. (2024) adapted a behavioural intervention for people with moderate to severe intellectual disabilities based on relaxation and graded exposure (Behavioural interventions to treat anxiety in adults with autism and moderate to severe intellectual disabilities: The BEAMS-ID Study). The feasibility of delivering the intervention was tested; it was also found to be acceptable to patients and their supporters, suggesting a definitive trial is warranted.

Cognitive Behavioural Theories around the Development and Maintenance of Anxiety Disorders and Problems

Behavioural theories have been criticised for failing to account for individual differences in the development and maintenance of mental health disorders and problems. Cognitive behavioural theories attempted to account for such differences by introducing cognitive mediators to these behavioural learning paradigms. In this way, individual differences in both predisposing factors, and the role of interpretation through cognitions feed into the development of psychological distress. Cognitive behavioural theories of anxiety disorders and problems suggest that in addition to behavioural learning, the influence of a person's cognitions, behaviours and bodily sensations interplay to affect their response to various stimuli (Beck, 1964 as cited in Beck & Fleming, 2021).

Cognitive Behavioural Therapy (CBT) represents a category of therapeutic approaches characterized by their collaborative nature, structured format, and emphasis on skill development. These interventions examine the complex relationships between cognitions, emotions, and behavioural patterns. The primary therapeutic goal

involves restructuring maladaptive thought processes and behavioural responses to enhance emotional regulation (Kaczurkin & Foa, 2015).

Cognitive Behavioural Therapy Interventions for Anxiety Disorders and Problems

When applied to anxiety disorders, CBT encompasses diverse therapeutic elements that may be tailored to individual needs. Common treatment modalities include educational components about the nature of anxiety, techniques for physiological relaxation, cognitive restructuring methods, systematic exposure protocols, interpersonal skill development, and structured approaches to problem resolution (Hofmann et al., 2012).

A primary CBT intervention aims to facilitate adaptive thinking patterns through cognitive restructuring and behavioural experiments. Cognitive restructuring promotes more adaptive and realistic interpretations of events by identifying cognitive traps (patterns of biased thinking that contribute to overly negative appraisals; Curtiss et al., 2021). This is frequently combined with behavioural experiments which can be used to facilitate cognitive change. Behavioural experiments involve encouraging a person to empirically test maladaptive beliefs to determine whether there is evidence supporting extreme thinking (Curtiss et al., 2021). Behavioural techniques (as described above) such as exposure to feared stimuli are also used within CBT interventions.

Two systematic reviews have specifically considered the literature around CBT interventions for anxiety in people with intellectual disabilities. Dagnan et al. (2018) reviewed 19 studies and reported positive outcomes of CBT interventions on anxiety for people with intellectual disabilities, although most of the reviewed literature consisted of single case studies. The most common interventions reported were psychoeducation

and approaches addressing beliefs or self-statements, with the most common behavioural interventions being relaxation and exposure-based approaches.

Fynn et al. (2023) systematically reviewed nine studies and reported positive outcomes regarding anxiety reduction in both child and adult populations with intellectual disabilities. Seven studies documented statistically significant anxiety improvements in 25% to 100% of participants (total N = 60) following CBT treatment protocols. However, reviewed studies lacked control group comparisons, alongside other design weaknesses that limit interpretability. Despite these constraints, the findings indicate that CBT interventions may represent a feasible and beneficial approach for addressing various anxiety disorders in this population.

A third review (Unwin et al., 2016) reviewed the literature for CBT programmes for anxiety and depression in adults with intellectual disabilities. While some studies reported an improvement in symptoms of anxiety, this was not reported for patients presenting with both anxiety and depression.

Interventions that have emphasised the cognitive aspects of CBT include Roberts and Kwan (2018). By focusing on various cognitive challenging interventions, they found a reduction in anxiety for people with mild (but not moderate) intellectual disabilities.

Theories Underpinning Third Wave Therapies Regarding the Development and Maintenance of Anxiety Disorders and Problems

Several therapies that have been developed from traditional behavioural models and have been described as ‘third wave’ interventions (Hayes, 2004). These include Compassion Focused Therapy (CFT), Mindfulness Based Cognitive Therapy (MBCT), Dialectic Behavioural Therapy (DBT), and Acceptance and Commitment Therapy (ACT).

Such therapies focus on the context and functions of psychological phenomena, and emphasize contextual and experiential change strategies (Hayes, 2004).

Within Compassion Focused Therapy, evolutionary processes are seen as having shaped our emotions to have different functions. These systems have been labelled as threat (fundamentally tied to threat detection and harm avoidance), drive (acquiring resources for survival, such as food or shelter) and soothe (resting and conserving energy). Problematic forms of anxiety can occur when these mechanisms are triggered inappropriately, too intensively, or last too long (Welford, 2010). Other third wave theories have broadly similar theoretical conceptualisations of the development and maintenance of anxiety disorders to traditional CBT models.

Third Wave Interventions for Anxiety Disorders and Problems

In contrast with traditional CBT models, third wave therapies seek to address problems trans diagnostically, helping a person to develop broad and flexible responses to distress, rather than developing strict protocols specifically around a diagnostic disorder. Experiential change is valued, and various strategies and practices employed to cultivate these shifts in affect (Hayes, 2004). There is also a focus on the meanings an individual draws from their experiences through techniques such as acceptance, mindfulness, cognitive defusion, dialectics, values, spirituality and relationships (Hayes, 2004).

CFT may address anxiety problems through rebalancing threat and soothe systems to enhance an individual's ability to self soothe through various techniques such as enhancing compassionate imagery and soothing rhythm breathing. MBCT focuses on a greater awareness of one's thoughts to allow non-judgemental awareness of the content of thoughts, along with a mindful state characterised by clarity and

vividness of current experience (Evans et al., 2016). Strategies to manage anxiety used in DBT also include building skills in mindfulness, alongside distress tolerance, emotion regulation, and interpersonal effectiveness (Malivoire, 2020). ACT focuses on building psychological flexibility, which involves accepting difficult thoughts and feelings while committing to actions aligned with personal values (Hasheminasab et al., 2015).

Patterson et al. (2019) systematically reviewed the literature around use of third wave therapies (mindfulness-based approaches, CFT, ACT and DBT) in people with intellectual disabilities and included 20 studies. The impact of these therapies on psychological distress or mental health problems was unclear. Whilst reduction in symptoms of anxiety and depression was found by some studies (e.g. Hall et al., 2013; Hardiman et al., 2018) and reductions in psychological distress reported by others (e.g. Crossland et al., 2017), some studies found no improvements (e.g. Ashworth et al., 2017), with Cooper and Frearson (2017) reporting a deterioration in mood. In terms of increasing psychological skills, firmer conclusions were drawn, with studies increasing skills around acceptance and non-judgement towards experience (Hall et al., 2013); self-compassion (Hardiman et al., 2018); reduced in self-criticism and unfavourable social comparisons (Clapton et al., 2017); willingness to experience aversive cognitions and emotions (Brown & Hooper, 2009; Pankey & Hayes, 2003); defusing from aversive cognitions and emotions (Pankey & Hayes, 2003); and taking action to meet behavioural goals (Pankey & Hayes, 2003).

Psychodynamic Theories around the Development and Maintenance of Anxiety Disorders and Problems

Psychodynamic ideas focus on the influence of unconscious psychological processes and the importance of early childhood experiences upon personality and behaviour. Psychodynamic theory suggest that anxiety symptoms, and anxiety disorders

result from unconscious conflicts. Anxiety was initially conceptualised as a buildup of libido that is not discharged, due to repression (Freud, 1895 in Pitman & Knauss, 2020). This was later reconsidered, with anxiety regarded as a safeguard to protect the ego's functioning from threatening impulses generated internally by the id (signal theory). Anxiety signals a threatening (often sexual or aggressive) impulse, which activates the ego's defence mechanisms, rendering it unconscious through repression. This was further developed and later Freud conceptualised anxiety to be the result of a conflict between id (the internal, unacceptable wish) and superego, (the standards and moral imputed onto the individual by society). While Freud's model was essentially concerned with internal, intrapsychic processes, later psychodynamic thinking has recognised the importance of interpersonal, relational, familial, and group experiences in the development of psychological symptoms (Pitman & Knauss, 2020).

Two specific models describe psychodynamic conceptualisations of the development of anxiety disorders, panic disorder and social anxiety disorder. Busch et al. (2012) suggest that panic attacks arise from unconscious conflicts related to dependency, attachment, and feelings of anger. Panic may be a disguised means of communicating a need for care, an aggressive and coercive attempt to attract caregiver's attention, or a means of punishing oneself due to guilt around individuation and dependency. They suggest interventions focus on exploring and understanding the emotional significance of panic, defining its meaning regarding to previous difficulties with caregivers, and working through these conflicts by recognizing how panic is displayed across various settings. Leichsenring et al. (2007) developed an integrative treatment for social phobia in which therapists explore affective components of shame and unrealistic demands the individual places on themselves in social situations.

These are combined with self-guided symptom exposure in the middle phase of treatment. The use of exposure is framed psychodynamically through relating it back to the therapeutic relationship and to underlying, relational themes experienced in other situations.

Psychodynamic Interventions for Anxiety Disorders and Problems

Psychodynamic interventions broadly focus upon individuals examining early childhood events and unconscious processes to gain insight into current difficulties. Therapists generally employ transdiagnostic approaches to distress, including a focus on the discussion of unconscious conflicts and their defences in relation to a wide range of anxiety disorders. Key features of short-term psychodynamic psychotherapy include a focus on affect and expressing emotion, and identifying patterns in actions, thoughts, behaviours and relationship (Blagys & Hilsenroth, 2000). Luborsky's (1984) model of supportive-expressive (SE) therapy represents a continuum of interventions to improve symptoms of distress. SE therapy includes expressive interventions, such as transference and defence interpretation, which are intended to promote insight and self-understanding. This can help the patient tolerate the uncomfortable affects and fantasies that result in problematic defences and produce anxiety. Conversely, supportive techniques help to enhance the patient's adaptive capacities and foster a secure therapeutic alliance. The therapist's ability to build a "holding" environment in which difficult affective and relational experiences can be explored collaboratively is key.

Therefore, whilst Freud suggested anxiety interventions should bring the threat into consciousness to help the patient understand that it no longer represents a present danger, current psychodynamic approaches focus on relational and affective

aspects of anxiety symptoms. It aims to reduce shame, range and guilt, with emotional insight being facilitated by the therapist making connections between past and current patterns of relationships, including within the therapeutic relationship.

A systematic review of the literature around psychodynamic interventions (psychoanalysis, psycho analytic and psychodynamic psychotherapy) for individuals with intellectual disabilities was conducted by Sheperd and Beail (2017). They included 13 studies with participants presenting with a wide range of difficulties including social, sexual. relationship and mental health difficulties. All studies were conducted in routine clinical practice. Two studies specifically looked at anxiety as a presenting issue (Newman & Beail, 2005; Newman & Beail, 2010). One study found some improvement in functioning (as measured by their ability to assimilate problematic events) (Newman & Beail, 2005), whilst the second study found no improvement in functioning post intervention. Overall, the studies suggest that psychoanalytic and psychodynamic psychotherapy can be effective, with high levels of client satisfaction reported. However, variability in findings across studies and a lack of robust methodologies means firm conclusions cannot be drawn.

Having considered various models of psychological interventions, I will now go on to synthesis what adaptations are required to these psychological interventions to make them accessible for people with an intellectual disability.

Adaptations Required to Psychological Interventions for Mental Health Disorders and Problems in People with Intellectual Disabilities

Despite the higher rates of mental health disorders and problems experienced by people with intellectual disabilities, developing accessible, effective psychological

interventions for this population has been challenging, with careful adaptations needed to ensure people can access treatments.

Psychological interventions have been adapted in various ways to accommodate the needs of people with intellectual disabilities. As mentioned, people with intellectual disabilities have idiosyncratic patterns of strengths and difficulties in their cognitive skills, as well as variability regarding social and emotional development, and the environment in which they live. However, common cognitive deficits, such as deficiencies in information acquisition and processing need to be accommodated (Surley & Dagnan, 2019) within psychological interventions. Difficulties in maintaining and generalising techniques learned in therapy are another key consideration (Stenfert Kroese, 2014).

CBT approaches for people with intellectual disabilities are often adapted to focus on behavioural, rather than cognitive strategies to reduce the reliance upon “talking” therapy components. The cognitive limitations of people with intellectual disabilities may make some cognitive techniques (e.g. identifying and altering core beliefs) less accessible, as they require sophisticated metacognitive and verbal skills (e.g. Tsimopoulou et al., 2018). Interventions for mood disorders and problems (such as anxiety) may also focus on behaviour management strategies rather than adapting internal cognitions (Acton et al., 2023), as changes in behaviour can be more easily identified by others. Surley & Dagnan (2019) reported that adaptations to CBT interventions for people with intellectual disabilities include simplification, language, activities, developmental level, use of directive style, flexible methods, involve caregivers, transference/countertransference and disability/rehabilitation approaches.

Studies frequently reported making adaptations across multiple categories, and that more sensitive categories of adaptations are required to fully understand the nuanced amendments made to these interventions. They suggested that a standardised framework reporting all categories of adaptations should be included in papers reporting psychological interventions adapted for this client group.

1.4 Mental Imagery and CBT

Despite an initial description of cognitions including both visual and verbal representations (e.g. Beck et al., 1974), traditional CBT approaches have focused on verbal rather than visual cognitions. More recently there has been a considerable interest in the role of mental imagery in the treatment of various psychological disorders in mainstream services. Mental imagery interventions have been found to be effective, easy to access, and able to produce clinically significant change within short interventions (Ramekers et al., 2024). This focus on mental imagery also fits with a reconceptualization of how change occurs in therapy from a focus on the content or maladaptive cognitions (what we think) to third wave approaches such as metacognitive processes (how we think) (Kunze et al., 2019). In this section, I will describe Kosslyn's model of mental imagery, consider how mental imagery may be implicated in the development and maintenance of anxiety disorders and problems, describe mental imagery-based interventions, and evaluate their efficacy.

Mental images are internal mental processes whereby perceptual information is accessed from memory, rather than directly from external stimuli. They can occur in one or more sensory modality and have been described as “seeing with the mind’s eye” or “hearing with the mind’s ear” and so on (Kosslyn et al., 2006). This perceptual

information can be combined in innovative ways and thus produce novel imagery, not simply replications of remembered events.

Kosslyn's Model of Mental Imagery

Kosslyn proposed a model of mental imagery encompassing four components: imagery generation, inspection, maintenance, and transformation (Kosslyn et al., 2006), with transformation having been expanded to include image manipulation (Pearson et al., 2013). In addition to these four aspects, Pearson et al. (2013) highlight the phenomenology, or subjective experience of mental imagery. These components are not independent, in that more than one aspect of mental imagery is often employed within the experience of having mental images. Whilst these four components have been extensively studied within experimental psychology and are well understood within the general population, they have not been systematically evaluated within people with intellectual disabilities.

Image Generation: This describes the process whereby stored topographical representations of objects are made explicit and accessible within the visual buffer (Kosslyn et al., 2006). It has been reported across different sensory modalities. Images can be rich and specific or general and low resolution.

Image Maintenance: This is a crucial part of mental imagery, allowing individuals to retain an image to complete additional tasks such as transformation or inspection. Images begin to fade as soon as they are generated, lasting only about 250 milliseconds (Kosslyn & Ochsner, 1994).

Image Inspection: Once an image has been generated the image is held within the visual buffer and Image Inspection can be achieved by shifting the attentional window

across it to encode its properties (Kosslyn et al., 2006). The spatial relationships between different parts of the image are encoded as the attentional window moves incrementally across the image (Kosslyn & Ochsner, 1994).

Image Transformation: Images can be transformed as if the person themselves is manipulating the object, or as if an external force was to manipulate the object (Kosslyn et al., 2006). Pearson et al. (2013) classify the manipulation of mental images in psychological interventions, such as image restructuring, as a form of image manipulation. Mental synthesis describes a combination of mental rotation and image restructuring, in which parts of an image are transformed and manipulated to produce new information or patterns (Pearson & Logie, 2019), and is linked with image restructuring, as used within Cognitive Behavioural Therapy (Pearson et al., 2013).

Mental Imagery and the Development and Maintenance of Anxiety Disorders and Problems

Distressing or intrusive mental imagery is associated with the development and maintenance of various psychological disorders and problems (Hackmann et al., 2011). Those experiencing depression have difficulties in generating positive mental imagery (Holmes et al., 2016a). Various mental health disorders such as bipolar disorder (Hales et al., 2011), generalised anxiety disorder (Tallon et al., 2020) and eating disorders (Hijne et al., 2021) are associated with intrusive and distressing mental imagery.

Mental imagery plays a crucial role in understanding how anxiety disorders and problems develop, improve, and respond to treatment, particularly through research using fear conditioning and extinction paradigms that incorporate mental imagery (see Mertens et al., 2020 for a review). Using mental imagery within these experimental frameworks enhances their ecological validity, making them more applicable to

psychopathology and therapeutic interventions (Mertens et al., 2020). Studies have demonstrated that fear responses, including avoidance behaviours (Kryptos et al. 2020), can be established through conditioning processes where aversive outcomes are purely imagined rather than actually experienced (Mueller et al., 2019; Soeter & Kindt, 2012). Furthermore, mental images can function as conditioned stimuli in their own right, with learned responses transferring to encounters with the actual stimuli (Lewis et al., 2013).

Mental imagery is key in the development and maintenance of anxiety disorders, due to its capacity to impact on emotion and motivation (Ji et al., 2019). Higher levels of anxiety are linked to an individual experiencing more vivid negative future imagery (Morina et al., 2011; Pile & Lau, 2018), and their ability to generate negative future imagery (compared to non-negative future imagery; Wu et al., 2016). Di Simplicio et al. (2016) found that higher anxiety levels were reported in people who are more able to imagine negative events and experience these images 'as if real', than for participants with less vivid imagery. Intrusive mental imagery (that is unwanted and comes to mind unbidden) is common in a range of anxiety disorders (Hirsch & Holmes, 2007). Examples include flashbacks in Post Traumatic Stress Disorder (PTSD) which are associated with avoidance, anxiety and distress. Mental images of feared contamination scenes are common in obsessive compulsive disorder (OCD) and are associated with distress, anxiety, and compulsive washing (Coughtrey et al., 2013). Patients with social anxiety often experience mental images of themselves appearing very anxious to others, or committing a social faux pas, which leads to anxiety and distress (Hirsch et al., 2003). 'Flash forward' images in depression describe suicide

related mental imagery that may be both distressing and comforting, is vivid, detailed and affect laden, and has qualities of being real and compelling (Holmes et al., 2007).

Mental imagery may also contribute to avoidance behaviours that maintain anxiety through aversive conditioning. Dadds et al. (2004) considered individual differences in imagery ability and the tendency to report specific aversions such as specific food phobias. Higher imagery ability was associated with higher levels of aversion, even when potential confounding factors (such as proneness to disgust) were controlled for. Having a greater ability to engage in the imagery of food consumption may strengthen the learned associations between the food stimuli and disgust, which then contributing to avoiding the food, thus maintaining the phobia. In conclusion, mental imagery could maintain anxiety directly (through vivid imagery of aversive scenarios) or indirectly through avoiding aversive images that results in avoidance behaviours) (Ji et al., 2019).

Mental Imagery Interventions for Mental Health Disorders and Problems

Mental imagery-based interventions may be an especially useful adaptation to traditional CBT interventions for people with intellectual disabilities for several reasons. Changing and manipulating mental imagery taxes different cognitive resources (i.e. visuospatial working memory) than manipulating verbal cognitions (which tend to tax verbal working memory, and brain regions underlying language production and comprehension; Alfred & Kraemer, 2017; Blackwell, 2019). Therefore, this may be more accessible for people with cognitive deficits including people with intellectual disabilities. Changing mental images result in stronger and faster shifts in affect compared to verbal cognitions (Holmes & Matthews, 2005; Blackwell, 2019).

Mental imagery can be used in various ways (e.g. promoting helpful imagery, changing the meaning of distressing images etc.) to target the mechanisms that underly the development and maintenance of psychopathology (Blackwell, 2021). This allows flexibility on using mental imagery with people with intellectual disabilities and suggests that for those who find specific aspects of mental imagery manipulation difficult (for example image transformation), other aspects of mental imagery could still be employed to target aspects of psychopathology (such as image generation). However, before mental imagery-based interventions can be developed and trialled in this population, various gaps in theoretical knowledge must first be addressed.

Various mental imagery interventions have been developed to treat psychopathology, including amongst those with limited cognitive skills (e.g. Schwarz et al., 2020). These techniques include imaginal exposure and systematic desensitisation, imagery rescripting, guided imagery, and promoting helpful imagery (Holmes & Matthews, 2010). Therapies such as Compassion Focused Therapy (CFT) include various mental imagery-based components such as developing compassionate images (through exercises such as the perfect nurturer or calm place imagery exercise). Whilst mental imagery interventions form a core part of psychological treatments for disorders (including anxiety disorders), they have not yet been adapted or investigated for use with people with intellectual disabilities.

The Efficacy of Mental Imagery Interventions

There is a growing body of evidence regarding the efficacy of mental imagery interventions both across different clinical populations, psychopathologies and types of mental imagery intervention. Two systematic reviews (Pile et al., 2021; Schwartz et al., 2020) have considered the efficacy of mental imagery interventions in children and

young people. Conroy and Hagger (2018) reported a systematic review and qualitative synthesis of mental imagery interventions around health behaviours. Other studies have focused on the efficacy of a specific mental imagery-based intervention for a mental health disorder or problem such as suicidal ideation (Knagg et al., 2022), low mood (Grol et al., 2017) or anxiety associated with undergoing an MRI scan (Shojaie et al., 2024). A systematic review and meta-analysis of the efficacy of mental imagery-based interventions for sub clinical social anxiety was reported by Thunnissen et al. (2024). Kroener et al. (2023) and Morina et al. (2017) systematically reviewed the literature regarding the effectiveness of a specific mental imagery intervention (imagery rescripting) across various clinical disorders.

Pile et al. (2021) systematically reviewed the literature around mental imagery interventions to reduce anxiety and depression in young people. They included 86 papers and considered seven categories of mental imagery interventions (imaginal exposure, systematic desensitisation, hypnosis, imagery rescripting, guided imagery, enhancing helpful imagery, and imagery-enhanced protocols). Across these, the most promising results were found for imagery rescripting for aversive memories, techniques targeting helpful imagery, and imagery-enhanced protocols. Imagery rescripting had the strongest evidence base, with the largest number of randomised controlled trials evaluating a similar approach and showing a large effect size. They concluded that mechanisms of change for imagery techniques are multiple and include reducing the power of distressing negative images through reducing avoidance, enabling emotional processing, updating their meaning or content, or a combination.

Schwarz et al. (2020) found various imagery techniques (e.g. imagery rescripting, emotive imagery, imagery rehearsal therapy, and rational emotive therapy with imagery)

had significant effects on symptoms of anxiety disorders and nightmares in children and adolescents. Mental imagery contributed to the maintenance of social anxiety disorder, post-traumatic stress disorder and depression in childhood. Adapting interventions to a child's developmental stage allowed them to be effective in reducing symptoms of distress.

Conroy and Hagger (2018) systematically reviewed and synthesised mental imagery interventions around health behaviours in 26 studies. Mental imagery interventions included mental simulations, visualisation, mental imagery, guided imagery, and functional imagery training. They found small, statistically significant positive effects of imagery on key outcomes including post-intervention health behaviour, intention, perceived control, attitude, and physiological outcome measures (such as weight loss, and resting heart rate). However, they noted the significant heterogeneity in results from studies.

Several studies report findings for mental imagery interventions to address specific psychological disorders or problems. Examples include Knagg et al. (2022), who conducted a small pilot study to compare a mental imagery-based intervention to address suicidal ideation in students, based on guided imagery and enhancing helpful images. They report large effect sizes on various clinical outcomes including reduced suicidal ideation. Grol et al. (2017) considered the role of generating positive imagery in reducing low mood in those with dysthymia. Participants receiving a positive mood induction procedure with imagery reported a significant increase in positive affect. Participants demonstrating anxiety about undergoing a magnetic resonance imaging (MRI) scan were randomly allocated to no intervention or a guided imagery intervention

(Shojaie et al., 2024). This study found significant reductions in state and trait anxiety for those receiving the imagery intervention.

Thunnissen et al. (2024) systematically reviewed the literature around imagery-based interventions that explicitly target negative images in (sub)clinical social anxiety. Twenty-one studies were included and generally involved one or two session interventions. Imagery interventions mostly used imagery rescripting with negative memories. Others used eye movement desensitization and reprocessing and imagery exposure with diverse intrusive images. Meta-analyses showed significant medium controlled effects on social anxiety and imagery distress and a nonsignificant effect on imagery vividness.

A systematic review of mental imagery rescripting (IR) across clinical disorders included 23 trials (Kroener et al., 2023). Participants had a range of diagnoses including Social Anxiety Disorder (SAD), Posttraumatic-Stress-Disorder (PTSD), Bulimia Nervosa, Borderline Personality Disorder, Obsessive-Compulsive Disorder, nightmare disorder, test anxiety, health anxiety, and Generalized Anxiety Disorder. The majority of studies (14 out of the total sample) involved single-session treatment protocols, demonstrating the potential for brief therapeutic interventions. Imagery rescripting demonstrated substantial clinical efficacy in reducing symptoms related to distressing mental images. The intervention showed consistent improvement across multiple time points, with large effect sizes observed from pre-treatment to post-treatment and maintained benefits at follow-up assessment. Whilst comparing the Imagery Rescripting intervention to a passive control group showed large effect sizes at post-treatment, comparing IR to an active control group resulted in a small effect. Particularly robust effects were documented for participants with Social Anxiety Disorder and Post-

Traumatic Stress Disorder subgroups. Additionally, imagery rescripting showed significant benefits for comorbid depressive symptoms across diagnostic categories. This review supports imagery rescripting as an effective brief therapeutic intervention for addressing clinical symptoms stemming from both prospective (future-oriented) and retrospective (past-oriented) distressing mental imagery.

Morina et al. (2017) also conducted a meta-analysis around imagery rescripting as a clinical intervention for aversive memories. They included 19 trials which included patients with diagnoses including posttraumatic stress disorder, social anxiety disorder, body dysmorphic disorder, major depression, bulimia nervosa or obsessive-compulsive disorder. The imagery rescripting intervention was administered over an average of 4.5 sessions (range, 1–16). Imagery rescripting was found to be largely effective in reducing symptoms from pretreatment to posttreatment and follow-up in the overall sample. When compared to passive control conditions, imagery rescripting resulted in a large effect size at posttreatment. Large effects from imagery rescripting were also seen on comorbid depression, aversive imagery, and encapsulated beliefs.

Whilst the evidence base for imagery based psychological intervention is growing, these studies highlight both the range of imagery interventions being used in clinical practice, and the complexity of such interventions. Interventions with the most robust evidence base include imagery rescripting, which requires participants to engage in meta cognitive work (thinking about their thoughts) as well as considering the meaning of images and evaluating these thoughts and beliefs.

Good quality psychological interventions are rooted in psychological theory. Having considered the theoretical underpinnings of anxiety disorders and mental

imagery interventions, I will now go on to describe how a bespoke psychological intervention was co-designed with people with intellectual disabilities to target anxiety.

1.5 Developing and Adapting Complex Psychological Interventions Using Inclusive Research Methods

Developing Complex Interventions

Developing an intervention is complicated, and there are multiple ways to approach this task. O’Cathain, Croot, Sworn et al. (2019) systematically reviewed the literature around intervention development and categorised approaches to this into eight categories. Table 1 details the taxonomy of approaches to intervention development described by O’Cathain et al. (2019).

Table 1

Taxonomy of Intervention Approaches (O’Cathain et al., 2019)

Category	Definition	Examples of approach
1. Partnership	The people for whom the intervention aims to help are involved in decision-making about the intervention throughout the development process, having at least equal decision-making powers with members of the research team	• Experience-based co-design (EBCD) • Co-production • Co-creation • Co-design, • Co-operative design
2. Target population centred	Interventions are based on the views and	• Person-based • User-centred

	actions of the people who will use the intervention	
3. Theory and evidence-based	Interventions are based on combining published research evidence and formal theories (e.g. psychological or organisational theories) or theories specific to the intervention	• MRC Framework for developing and evaluating complex interventions • Behaviour change wheel • Intervention mapping
4. Implementation-based	Interventions are developed with attention to ensuring the intervention will be used in the real world if effective	• Reach, Effectiveness, Adoption, Implementation, Maintenance (RE-AIM)
5. Efficiency based	Components of an intervention are tested using experimental designs to determine active components and make interventions more efficient	• Multiphase optimization strategy • Multi-level and fractional factorial experiments • Micro-randomisation trials
6. Stepped or phased based	Interventions are developed through emphasis on a systematic overview of processes involved in intervention development	• Six essential Steps for Quality Intervention Development (6SQUID) • Five actions model
7. Intervention-specific	An intervention development approach is	• Patient decision support or aids • Group interventions

	constructed for a specific type of intervention	
8. Combination	Existing approaches to intervention development are combined	• Participatory Action Research based on theories of Behaviour Change and Persuasive Technology (PAR-BCP)

This project combines two of these categories, a theory and evidence-based approach with a partnership approach. Within the theory and evidence-based approach, published research evidence is combined with formal psychological theories specific to the intervention. Examples of this approach include the Behaviour Change Wheel, Theoretical Domains Framework and the Medical Research Council (MRC) Framework for Developing and Evaluating Complex Interventions (Craig et al, 2008; Skivington et al, 2021). The partnership approach is characterised by the involvement of the people who the intervention aims to help being involved with decision making throughout the development process and holding at least equal decision-making powers with members of the research team. Examples of such approaches include Co-production, Co-design, and Experience-Based Co-Design (EBCD).

The MRC and NIHR Framework for Developing Complex Interventions

An update to guidance from the Medical Research Council (MRC) around developing complex interventions (Craig et al., 2008) had been commissioned by the MRC and National Institute for Health and Care Research (Skivington et al., 2021). This emphasised the need for complex intervention research to take into account the complexity that arises both from the intervention's components and from its interaction with the context and systems in which it is implemented. This guidance divided

complex intervention development into 4 phases: development or identification of the intervention, feasibility, evaluation, and implementation. This project is concerned with the first of these phases, that of developing an intervention, with subsequent phases to be considered in later work (see Chapter 7). Figure 1 illustrates the elements from the MRC and NIHR framework for developing complex interventions (Skivington et al., 2021) followed within this thesis to guide the choice of research methods.

Figure 1

Aspects of MRC and NIHR Framework for Developing Complex Interventions Used Within This Thesis to Inform Choice of Research Methods

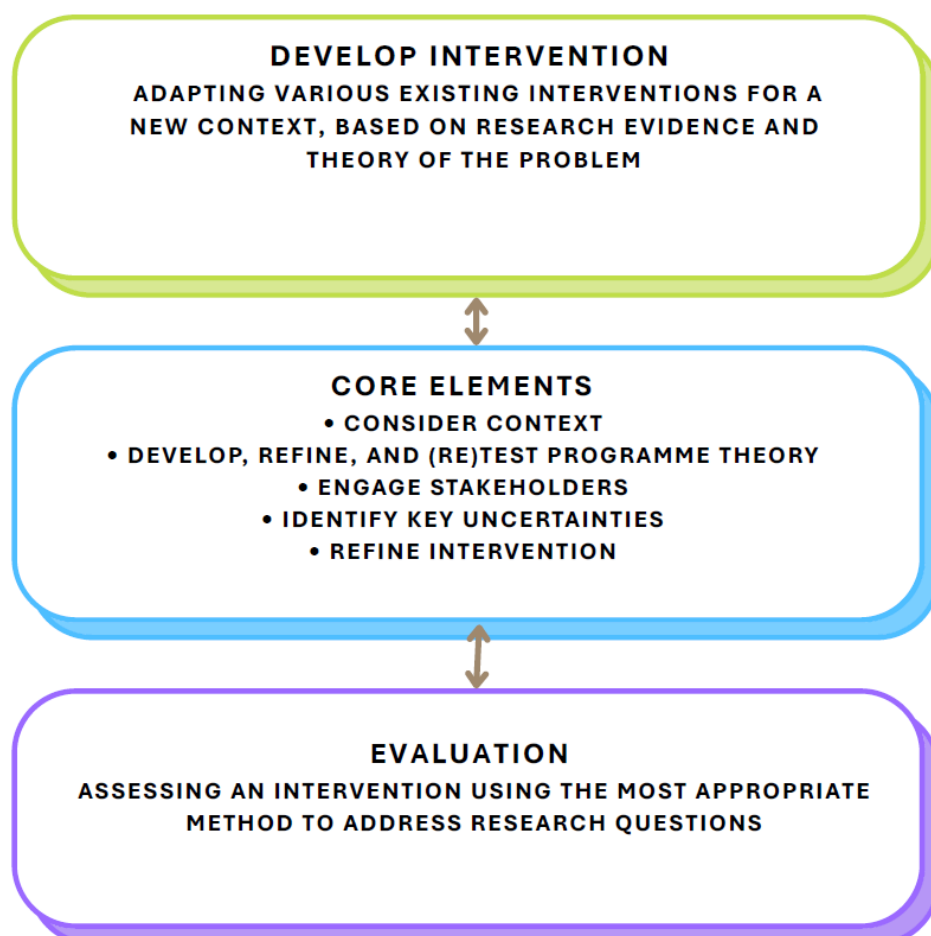


Table 2 summarises the aspects of the framework which were followed when developing and testing the mental imagery-based anxiety intervention (named Co-MAID). Co-MAID was chosen as the name of the intervention by the project PPI group as it was a **Co**-Designed **M**ental Imagery intervention for **A**nxiety in people with mild to moderate **I**ntellectual **D**isabilities. Table 1 also provides some information about how the aspect of the framework was addressed within this thesis, and the specific study or studies that addressed this aspect.

Table 2

How Aspects of MRC and NIHR framework for Developing Complex Interventions are Used to Drive the Choice of Methods Within the Thesis

Aspect of framework	Consideration within thesis	Main areas/ studies addressing this aspect
Core elements		
<i>Engage Stakeholders</i>	Detailed within Chapter 1 subsection 'Co-Designing a mental imagery intervention for people with mild to moderate intellectual disabilities'	- Chapter 1 subsection 'Co-Designing a mental imagery intervention for people with mild to moderate intellectual disabilities' - EBCD paper (Chapter 5)
<i>Identify key uncertainties</i>	Can people with intellectual disabilities engage with all aspects of mental imagery?	- Systematic review to collate and synthesis evidence for use of mental imagery across different psychological fields (Chapter 2) - Investigation of phenomenology of mental imagery in people with intellectual disabilities (Chapter 4)
<i>Consider Context</i>	Adapting the intervention to fit different contexts	Co-development of intervention using EBCD through focus groups and workshop (Chapter 5)

<i>Develop, refine and retest Programme Theory</i>	Programme theory was continually refined throughout the project and is detailed in Discussion section (with a logic model to visually represent some aspects of the programme theory)	Updated programme Theory detailed in Discussion section (Chapter 7)
<i>Refine intervention</i>	Intervention refined throughout the development and testing process but specifically formally captured at three points (through focus groups and the workshop during EBCD phase, at mid-point of SCED phase)	- Co-development of intervention using EBCD through focus groups and workshop (chapter 5) - Mid intervention refinement using FRAME when using intervention in NHS settings (Chapter 6)
Develop Intervention		
<i>Adapt existing interventions for new context</i>	To develop the intervention based on framework described by O’Cathain et al. (2019) including:	
	Plan development process	Developed as part of funding application to NIHR for Clinical Doctoral Fellowship
	Involve stakeholders	Developed as part of funding application to NIHR for Clinical Doctoral Fellowship. See Chapter 1 subsection ‘Use of inclusive research within the thesis’
	Convene a team	Developed as part of funding application to NIHR for Clinical Doctoral Fellowship
	Review published evidence	Chapters 2 and 3
	Draw on existing theories	Chapter 1
	Articulate programme theory	Chapter 7
	Undertake primary data collection	Chapter 4
	Understand context	Chapter 5
	Consider real world delivery setting	Chapter 6
	Design and refine intervention	Chapter 5
	End development phase	Chapter 7

Evaluation		
<i>Assess intervention using most appropriate method to address research questions</i>	• What was the effect of the intervention on levels of anxiety and daily mood for participants? • How acceptable did participants and supporters find the intervention?	• Initial testing of Co-MAID using Single case Experimental Design and semi structured interviews to assess acceptability of the intervention (Chapter 6)

Use of Inclusive Research Within the Thesis

Based on the existing literature and using the MRC and NIHR framework for Developing Complex Interventions, this thesis reports the co-development of a mental imagery intervention for people with mild to moderate intellectual disabilities experiencing anxiety. Co-design refers to working alongside people with intellectual disabilities as equal partners in the research process. As well as specifically working with co-researchers in the design of the intervention (using the Experience Based Co-Design framework), I followed wider principles of inclusive research throughout the planning, conducting, analysis and dissemination of this work.

For this project, this meant that people with intellectual disabilities and stakeholders (their family members and those working directly to support them) were involved in the initial planning of this project and shaped the development of all stages of this research. I was able to work with a group of people with mild to moderate intellectual disabilities (who had a range of additional mental and physical health needs) who met with me regularly throughout the whole project. They named themselves the STAR group (Sharing Thoughts About Research). At times, we met more frequently (every 2-4 weeks), and at other times we had longer gaps between meetings.

Similarly, I met with my Stakeholder group regularly (usually every 6 weeks) throughout the project to guide thinking about accessibility, dissemination and future funding, as well as taking part in research tasks such as data analysis and completing ethics applications.

Ethical Principles Underpinning Inclusive Research

There are numerous important arguments around the intrinsic value of conducting inclusive research, some of which are further explored in Chapter 3 (in which the role of people with intellectual disabilities in inclusive health and care research is reviewed and synthesised). Such arguments include producing more accessible, accurate and relevant research and ensuring that the research conducted makes a meaningful difference to the lives of people with intellectual disabilities (O'Brien et al., 2022). Alongside these goals, there are various ethical imperatives for engaging in inclusive research, which have been detailed in several reviews (e.g. Bigby et al., 2014).

Fundamentally, people with intellectual disabilities want to be involved in research about them and should have influence over the research topics that are chosen, what research methodologies are employed, and how research is carried out. Inclusive research ensures a range of views and experiences are discovered and promotes social inclusion (e.g. O'Brien et al., 2014). Excluding people with intellectual disabilities from research (both as research participants and as co-researchers) is ethically unacceptable, and as researchers, meaningful inclusion must be pursued (Embregts et al., 2018). To do this, we must develop the skills, knowledge and confidence of people with intellectual disabilities as they work alongside academics

and other partners as co-researchers (Tuffrey-Wijne et al., 2020; Johnson & Walmsley, 2003). Challenges around ensuring the genuine collaboration of people with intellectual disabilities in research continue (e.g. Riches et al., 2020) and are discussed in both Chapter 4 and Chapter 7.

1.6 Epistemological Stance

One's epistemological stance refers to our thoughts and understandings around the theory of knowledge. It is concerned with questions such as 'what is reality?' and 'what constitutes valid knowledge?'. This, combined with one's ontology (understanding of 'what is reality?'), leads to a theoretical perspective, which informs about what approaches we can use to gather knowledge. This subsequently informs our choice of methodology (the procedures used to acquire knowledge) and the methods or tools used to do this, as well as the sources of data we can collect (Patel, 2015).

A broad spectrum of epistemological stances have been described within the field of research, ranging from positivism (with an emphasis on observable facts and measurable data, understanding knowledge as something to be discovered and measured) to interpretivism (focused on subjective meanings and understandings, in which the role of the researcher influences and shapes finding, understanding knowledge as being socially constructed and influenced by context).

My epistemological stance sits between critical realism and constructivism. While critical realism accepts the existence of an objective, external reality, it maintains that our understanding of this reality is inherently shaped by social processes, making knowledge subjective in nature. Proponents of critical realism contend that, contrary to positivist assumptions, we cannot simply observe phenomena and derive universal laws without recognizing that our perspectives, beliefs, and interpretations are products

of social construction and remain subject to change (Koopmans & Schiller, 2022; Ormston et al., 2014). Critical Realism fits well with methodologies used within this thesis such as Experience-Based Co-Design, and Template Analysis.

However, constructivism sits more towards the interpretivism end of the spectrum and holds that we can only know reality through accessing others' subjective accounts of their experiences, and those realities are a function of their interaction with the world around them. This is in line with qualitative methodologies, and especially those which emphasise the study of phenomenology (the study of experience) and hermeneutics (the theory of interpretation), such as Interpretative Phenomenological Analysis, as well as other qualitative methods used within the thesis such as Thematic Analysis and co-design.

This thesis also uses Single case Experimental Design, in which experiences such as anxiety levels of daily mood are translated into numerical values and measures over time, with the aim of identifying changes in subjective experiences through positivist methodologies. Whilst initially this may appear at odds with the stance outlined above, such methods are combined with qualitative data (including interviews focusing on the individual's subjective experience of completing the intervention). This mixed methods approach fits with the overarching stance of pragmatism.

Pragmatism is an epistemological position that focuses on 'knowledge that works' in a particular situation. Pragmatists work with whatever tools or methods shed light on the issue of enquiry, and thus, rather than focus on universal principles that guide exploration, we are left with practical action (Gillespie et al., 2024). Pragmatism gives researchers "permission" to be less epistemologically consistent and, instead, use any methods that contribute to the issue at hand (Seale, 1999). Pragmatist

researchers are concerned with reality as the background against which positions and perspectives are formed and changed. They also see reality as the world in which these positions and perspectives exist.

The pragmatic researcher seeks to understand the phenomenon being studied in a systematic manner. They understand the knowledge uncovered regarding the phenomenon as reflecting subjective perspectives taking place as people encounter the world, a dynamic and changing reality. This requires a range of different methodologies, because no single research method or source of data could account for differences in perspective and the study of human action (Gillespie et al., 2024) and thus fits with the multiple methodologies described within this thesis. Implications for pragmatism in terms of methodology include avoiding analytical reductionism (reducing complex phenomena to simple processes) and methodological fixedness (allowing for novelty and innovation). Aspects of the thesis that reflect these are the in-depth exploration of the phenomenology of mental imagery in Chapter 4 and the use of creative methods to co-create a range of research dissemination materials (Chapter 7). Therefore, pragmatism encourages plurality regarding theoretical perspectives, datasets, data collection tools, and analytical methods (Gillespie et al., 2024).

1.7 Thesis Outline and Aims

The aims of this thesis were to develop and conduct initial testing of a novel, co-designed, mental imagery-based intervention for anxiety in people with mild to moderate intellectual disability. The specific aims are:

1. To synthesise the literature around the abilities of people with intellectual disabilities to engage with mental imagery (the generation, maintenance,

inspection, and transformation of mental images), and the role of mental imagery within existing psychological interventions for people with intellectual disabilities.

2. To synthesise the literature regarding inclusive research across health and social care topics, to understand the various roles assumed by people with intellectual disabilities involved with inclusive research, and their experiences of undertaking such roles.
3. To explore the phenomenology of mental imagery in people with intellectual disabilities, to understand what factors facilitate or hinder the development and use of mental imagery in this population, and to consider the implications of these in terms of developing a psychological intervention
4. To co-develop an anxiety intervention using components of mental imagery for people with mild to moderate intellectual disabilities
5. To conduct initial testing and refinement of the intervention in NHS settings, and to assess acceptability.

Chapter Outline

Chapter 2 – Study 1

Whilst psychological interventions focused on mental imagery are being increasingly used in mainstream services, this had not translated into intellectual disability services. Despite clinical impressions to the contrary, a deficit-based assumption appears to prevail, suggesting this population are not capable of generating or manipulating mental images. Therefore, I undertook a systematic review of the literature to gather evidence for the use of mental imagery by people with Intellectual Disabilities across a range of fields including sports science, experimental paradigms and clinical psychology. Evidence from 41 studies showed people with intellectual

disabilities were able to engage with all aspects of generating and manipulating mental imagery and identified factors that facilitated such processes.

Chapter 3 – Study 2

Having established that people with intellectual disabilities are able to engage with all aspects of mental imagery generation and manipulation (with appropriate adaptations and scaffolding), I considered how a mental imagery-based psychological intervention could best be developed for this population. In terms of my ethical stance and beliefs, people with intellectual disabilities should be involved actively in research about them. Therefore, a second systematic review considered current models of inclusive research practice with people with intellectual disabilities in health and social care fields, and the factors that impede or promote their active involvement.

At this stage I recruited two groups to work alongside me, to shape the overall research and to be actively involved as co-researchers in parts of specific research projects. The first group consisted of 8 people with mild to moderate intellectual disabilities and the second was a group of 8 stakeholders (family members, advocates, and service managers).

Chapter 4 – Study 3

Having understood more about mental imagery from a theoretical perspective, I then explored how people with intellectual disabilities experienced this phenomenon. I used Interpretative Phenomenological Analysis (IPA) to allow a detailed nuanced understanding of the lived experiences of my participants and incorporated creative visual techniques into my data collection, allowing me to synthesise the participants' verbal accounts with images created during our time together.

Chapter 5 – Study 4

Based on these experiential and theoretical underpinnings regarding mental imagery in people with intellectual disabilities, I embarked on co-designing an intervention along with people with intellectual disabilities and other stakeholders. I used the formal framework of Experience Based Co-Design (EBCD) to guide this intervention development, alongside guidance from Medical Research Council and National Institute of Health and Care Research in developing complex interventions (Skivington et al, 2021). EBCD provided a structure through which I could ensure that principles of co-design were embedded and rigorously followed throughout the intervention development stage.

Chapter 6 – Study 5

Having completed the design of the intervention, I then embarked upon a process of initial testing and refining the intervention, using single case experimental design (SCED) and process evaluation to explore issues of acceptability for participants and their supporters. The use of SCED allowed for testing with a small number of participants, whilst employing randomisation across multiple baselines to strengthen the robustness of the methodology.

Chapter 7 - General Discussion

This chapter summarised the results of the thesis and detailed how results were disseminated. It then considered the implications for treating anxiety in people with intellectual disabilities in clinical practice, theoretical developments (including a detailed programme theory and revised logic model for the intervention) and detailed plans for future feasibility testing of the intervention.

CRedit Statements are provided for each paper to clarify the role of each contributor.

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Chapter 2

A Systematic Review and Narrative Synthesis of Mental Imagery Tasks in People with an Intellectual Disability: Implications for Psychological Therapies

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Abstract

Mental imagery is recognised for its role in both psychological distress and wellbeing, with mental imagery techniques increasingly being incorporated into psychological interventions. In this systematic review and narrative synthesis (PROSPERO 2021: CRD42021240930), we identify and evaluate the evidence base for the phenomenon and phenomenology of mental imagery in people with intellectual disabilities, to ascertain the applicability of such interventions for this population. Electronic searches of nine databases and grey literature identified relevant publications. Two reviewers independently assessed titles and abstracts of retrieved records (n = 8609) and full-text articles (n = 101) against eligibility criteria. Data were extracted and quality appraised. Forty-one papers met our eligibility criteria. The quality and designs were variable. Mental imagery was facilitated through ensuring participants understood tasks, providing opportunity to rehearse tasks (including using concrete prompts) and using scaffolding to help participants elaborate their responses. People with intellectual disabilities can engage with mental imagery, with appropriate adaptations, although the associated phenomenology has not been thoroughly investigated. Mental imagery interventions may be useful for people with intellectual disabilities with appropriate modifications.

Highlights

- Evidence for different aspects of mental imagery in people with intellectual disabilities was consolidated.
- People with intellectual disability can use mental imagery but the evidence was of mixed quality.
- Adaptations to facilitate mental imagery were outlined and the applications for therapy considered.
- Implications for psychological interventions are explored

Keywords

Intellectual disability; Mental imagery; Narrative synthesis; Phenomenology; Psychotherapy; Cognitive behavioural therapy

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Declaration of Competing Interest

The authors declare no conflicts of interest.

Data Availability

Data will be made available on request.

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Introduction

Mental imagery interventions are a core component of Cognitive Behavioural Therapy (CBT) (Saulsman et al., 2019). They are included in treatment protocols for treatment resistant psychological disorders where ‘standard’ psychological interventions have previously had limited effects, including depression (Wheatley et al., 2007) and Obsessive Compulsive Disorder (Maloney et al., 2019), and to address transdiagnostic psychological issues (Landkroon et al., 2021; Morina et al., 2017). Such interventions are powerful, as mental imagery has a greater effect on emotion than verbal thoughts of a similar content (Holmes & Mathews, 2005) through several pathways (Holmes & Mathews, 2010) and thus has a role both in maintaining psychological disorders and in psychological treatments. However, whilst adapted CBT is a recommended psychological intervention for various disorders in people with intellectual disabilities, many interventions described as CBT in this population may actually be behavioural interventions (Sturmey, 2004). Mental imagery interventions do not require the cognitive and verbal skills of some traditional CBT interventions such as challenging cognitions or creating alternative cognitive appraisals, potentially making them more accessible for this population. Therefore, incorporating mental imagery interventions into psychological treatments for people with intellectual disabilities may be clinically important. However, a review and synthesis of any differences in the ability of people with intellectual disabilities to engage with mental imagery is first required.

1.1 Mental Imagery

Mental images include a range of experiences from sudden, intrusive memories of past events to deliberately constructed daydreams (Holmes & Mathews, 2010), and

have been described as occurring when perceptual information is accessed from memory giving “rise to the experience of ‘seeing with the mind's eye’, ‘hearing with the mind's ear’ and so on” (Kosslyn et al., 2001). Mental imagery can occur in any of the five senses, but often include a visual image, or picture. By contrast, perception occurs when information is directly registered from the senses. Mental images can involve several sensory modalities and represent complex scenarios which can alter over time. They can be fleeting and fragmentary and can incorporate previously perceived events and objects in novel and innovative ways.

Mental imagery can be considered from various angles, including from a cognitive perspective (examining the different operations involved in mental imagery), through exploring the phenomenology of mental imagery, and by considering the links between mental imagery and psychopathology.

Kosslyn's Cognitive Stages Model of Mental Imagery

Kosslyn's (1980; Kosslyn, 1994) computational model of mental imagery aims to establish which cognitive systems are associated with the generation and manipulation of mental images and the processing subsystems that underlie the functioning of mental imagery in the brain. It is based on perceptual anticipation theories. This centres on the idea that mental images are experienced when one so strongly anticipates seeing an object that a depictive representation of the object is created in the topographically organised visual cortex (Kosslyn et al., 2006). This model has shaped research within both experimental cognitive psychology, and neuropsychology (Pearson et al., 2013).

Kosslyn's model encompasses four components of mental imagery: imagery generation, inspection, maintenance, and transformation (Kosslyn et al., 2006), with transformation having been expanded to include image manipulation (Pearson et al., 2013).

In addition to these four aspects, Pearson et al. (2013) highlight the phenomenology, or subjective experience of mental imagery. These components are not independent, in that more than one aspect of mental imagery is often employed within the experience of having mental images. These components of mental imagery have been studied extensively within experimental psychology and are well understood within the general population. However, they have not been systematically evaluated within a population with intellectual disabilities.

Image Generation. This is the process whereby stored topographical representations of objects are made explicit and accessible within the visual buffer (Kosslyn et al., 2006). Images can be rich and specific or general and low resolution (with these general images taking less time to generate and being less memorable; Cornoldi et al., 2014). Image generation has been reported across different sensory modalities.

Image Maintenance. Images begin to fade as soon as they are generated, lasting only about 250 ms (Kosslyn, 1994). Therefore, for any manipulation or inspection of an image to be conducted, active maintenance of the image is required. Image maintenance is a crucial part of mental imagery, allowing individuals to retain an image to complete additional tasks such as transformation or inspection. Within the model,

such maintenance is achieved by the re-activation of visual memory representations in an Object Properties Processing subsystem (Kosslyn, 1980; Kosslyn et al., 2006).

Image Inspection. Within the computational theory, once an image has been generated the image is held within the visual buffer and it can be inspected by shifting the attentional window across it to encode its properties (Kosslyn et al., 2006). The spatial relationships between different parts of the image are encoded as the attentional window moves incrementally across the image (Kosslyn, 1994). Visual scanning tasks are often used to test mental inspection skills. There is significant evidence that the time it takes a participant to scan across an image increases directly with the distance scanned (Denis & Kosslyn, 1999).

Image Transformation. Images can be transformed as if the person themselves is manipulating the object, or as if an external force was to manipulate the object (Kosslyn et al., 2006). Pearson et al. (2013) classify the manipulation of mental images in psychological interventions, such as image restructuring, as a form of image manipulation. Mental synthesis describes a combination of mental rotation and image restructuring, in which parts of an image are transformed and manipulated to produce new information or patterns (Pearson & Logie, 2000), and is linked with image restructuring, as used within Cognitive Behavioural Therapy (Pearson et al., 2013). Image transformation has also been studied in auditory (Zatorre, 2012) and haptic (Miquée et al., 2008) modalities.

1.2. Phenomenology of Imagery

There appears to be a continuum of experience of mental imagery, with some neurologically intact people reportedly unable to access any mental images (Nelis et

al., 2014), whilst others are highly skilled in imagery (Macintyre et al., 2013). The subjective vividness of mental images includes the luminosity and clarity of an image, as well as how similar the subjective imagery experience is to actual perceptual experience (Pearson et al., 2001). Other phenomenological imagery characteristics that have been investigated in clinical populations without Intellectual Disability include a sense of 'nowness' (Hales et al., 2011) and whether the imagery is experienced from a field or observer perspective (Day et al., 2004).

1.2 Mental Imagery and Psychopathology

There is a growing interest in how mental imagery can treat psychopathology (Blackwell, 2019; Holmes & Mathews, 2010). Whilst experimental psychology has explored everyday experiences of mental imagery, clinical psychology has focused on the role of intrusive and distressing images in maintaining psychological disorders (Hackmann et al., 2011). Several mechanisms through which mental imagery impacts upon emotion have been proposed (Holmes & Mathews, 2010), suggesting implications for psychological interventions. Indeed, a range of mental imagery interventions have been shown to be effective across various populations and disorders (e.g., children and adolescents, Schwarz et al., 2020; social anxiety disorder; Lee & Kwon, 2013). Mental imagery interventions can promote helpful imagery, reduce negative imagery, change the person's relationship with the imagery (through meta-cognition) or use imagery competing tasks (e.g., Tetris) (Holmes et al., 2007).

1.3 Mental Imagery and Intellectual Disabilities

People with intellectual disabilities indisputably experience cognitions, and therefore presumably also experience mental imagery, a type of cognition. However,

little empirical information exists regarding mental imagery in this population. Within Kosslyn's model (Kosslyn et al., 2006), the four mental imagery components are implemented through the combined action of several more basic, domain-general algorithmic neurocognitive components and processes. Ability to experience mental imagery reflects these components and processes (Heyes et al., 2013), which includes information processing speed, general cognitive development, and executive functioning including attentional control, response inhibition, and working memory (Pearson, 2019), all of which are impaired in people with intellectual disabilities (Danielsson et al., 2012). Such impairments in these domain-general cognitive skills may impact the experience of mental imagery.

However, cognitive impairments exist in clinical populations without intellectual disabilities (e.g., those with PTSD and bipolar disorder), and whilst such clients may require scaffolding to optimally engage with mental imagery interventions (e.g., Holmes et al., 2019), their cognitive limitations are not a barrier per se. Understanding how, if at all, mental imagery may differ in people with intellectual disabilities, is an essential precursor to developing a suitable mental imagery intervention for the population.

People with intellectual disabilities are at increased risk of developing various mental illnesses (Helps, 2015) and are less able to access accessible, effective psychological interventions (Vereenoghe & Langdon, 2013). To understand how mental imagery psychological interventions need to be adapted to benefit people with intellectual disabilities, a comprehensive review and synthesis of the existing literature was completed.

1.4 Aim of the Review

The aim of this systematic review was to synthesise the literature about mental imagery in people with intellectual disabilities, to understand similarities and differences compared to the general population (in relation to Kosslyn's model of mental imagery), understand how mental imagery is currently used within therapeutic interventions, and appraise the quality of this literature. Through this, gaps in the literature were identified, allowing future research to be targeted to such areas, advancing the understanding of mental imagery in people with intellectual disabilities and potentially driving innovation in clinical intervention.

1.5 Review Questions

1. What do we understand about the abilities of people with intellectual disabilities to engage with mental imagery (the generation, maintenance, inspection, and transformation of mental images)?
2. What do we understand about the phenomenology of mental images in people with intellectual disabilities, compared to the general population?
3. What do we understand about the role of mental imagery within existing psychological interventions for people with intellectual disabilities?

Methods

The systematic review is reported in line with current PRISMA-S guidelines (Page et al., 2021; Rethlefsen et al., 2021).

2.1 Eligibility Criteria

Studies were included if they: (a) involved the assessment of mental imagery (the generation, maintenance, inspection, and transformation of a mental image) or involved mental imagery as a core component of a reported intervention imagery (interventions deemed to contain a core component of mental imagery included EMDR, Imagery Rehearsal, Imagined Exposure) or report the phenomenology of mental imagery, (b) were conducted with people with intellectual disabilities and (c) were published after 1980 (the year of publication of the Diagnostic Statistical Manual of Mental disorders, 3rd ed.; American Psychiatric Association, 1980).

Studies were excluded from the review based on one or more of the following criteria: (a) including data from autistic people or mixed aetiology groups where data for individuals with solely intellectual disabilities were not reported separately, (b) most participants did not meet criteria of intellectual disability (participants did not have a diagnosis of intellectual disability, or an IQ of below 70, or mean group IQ below 75), (c) the paper did not report an empirical research study, (d) mental imagery did not form a core component of a task or intervention (i.e. a mental imagery task used on a one-off basis as part of a broader psychological intervention, or tasks described could be solved using mental imagery or another strategy e.g. Theory of Mind or False Belief task).

2.2 Information Sources

Databases. The following electronic databases were searched: AMED (HDAS), BNI (HDAS), CINAHL (HDAS), EMBASE (Ovid Online), MedLine (HDAS), PsychINFO

(HDAS) on 25 May 2021. No additional relevant results were identified on re-running searches on 31 August 2021, or 6 March 2022. No search filters were used.

6.2.1. Grey Literature and Registries

The following sources of the grey literature were initially searched on 24 April 2021, with searches re-run on 31 August 2021 and 6 March 2022, with no new results identified.

Google scholar (<https://scholar.google.com/>) was searched using the terms (intellectual disability OR learning disability) AND mental imagery. The first 100 results were screened for inclusion, and no new articles were identified as relevant.

Cochrane Library was searched using the terms ‘mental imagery’ in all text and ‘intellectual disability’ or ‘learning disability’ in Title, Abstract, Keywords. Forty-five Cochrane reviews were identified, none of which were relevant. 2394 trials were identified, seven of which were identified as relevant. Of these seven, five were duplicates of results identified through databases, and two did not meet inclusion criteria.

The Cochrane Central Register of Controlled Trials (<https://www.cochranelibrary.com/central>) was searched to identify ongoing trials using MeSH terms: “Developmental Disabilities”, “Intellectual Disability” and “Learning Disabilities”. No relevant results were identified.

The British Library EThOS database of dissertations was searched using the search terms (‘learning disability’ OR ‘intellectual disability’) AND ‘image’. This returned

19 results, one of which was a duplicate of a record identified through databases, and 18 did not meet inclusion criteria.

The Conference Proceedings Index was searched through Web of Science and 41 results were obtained. Three results were duplicates of a result obtained through database searches, and the rest did not meet inclusion criteria. Twenty percent of results were screened by a second rater (NH) and an inter-rater reliability of ($k = 1$) was obtained.

6.2.2. Citation Searching

Backward and forward citation searching was undertaken. Reference lists of all included articles were manually screened to identify additional studies. Forward citation searching was conducted by looking up each included article on Google Scholar and manually screening each article which cited that paper. This was initially conducted on 7 June 2021, re-run on 31 August 2021 and 6 March 2022 and identified three additional studies.

2.3 Full Search Strategy

The reproducible searches for all databases are available at Warwick Research Archive Portal <http://wrap.warwick.ac.uk/156431> and provided in Appendix 1. The search strategies were peer reviewed by two senior academics (PL and CS), and by an experienced librarian (SJ). The search was registered with PROSPERO on 22 April 2021 PROSPERO 2021 CRD42021240930 Available from: https://www.crd.york.ac.uk/prospERO/display_record.php?ID=CRD42021240930

2.4 Selection Process

Results were exported into EndNote, and 5583 duplicates were removed using EndNote's duplicate identification strategy. Results were then exported to Rayyan for screening. At this stage an additional 970 duplicate results were identified and removed.

The initial screening of the 8609 titles and/or abstracts of records was conducted by OH, with a random sample of 20% double reviewed by an independent second rater (NH) who was blind to the other researcher's ratings. Three abstracts were translated from French to determine their eligibility. None of these papers were eligible for inclusion. Where data were reported for the same participants across multiple papers (e.g., dissertation thesis and peer reviewed article), the peer reviewed journal article was included in the review and double counting was avoided. One record was not obtainable (Hartley, B. A. (1983). Directed Positive Imagery as Reinforcement of Academic Behaviour in Trainable Mentally Handicapped Students. Florida Educational Research and Development Council Research Bulletin, 17(3), n3).

The review of title and abstracts was completed using Rayyan software. There was an inter-rater reliability of 97%, $k = 0.82$ at this stage, with 17 disagreements discussed and consensus reached on all results. This resulted in 101 articles requiring full text screening, which was also done through Rayyan software. OH and NH independently read and appraised 100% of these texts, resulting in an inter-rater agreement level of 95%, $k = 0.90$. The five articles which were conflicted decisions at this stage were resolved through discussion, and 100% agreement was reached on all studies. One additional study (Unwin et al., 2016) was excluded at data extraction stage

as it became apparent that it did not meet inclusion criteria. Therefore, 41 articles met the full inclusion criteria for this review (see Fig. 1).

2.5 Data Extraction

Data were extracted using an amended form based on Cochrane Public Health Group. The data extraction form was piloted by NH and OH on three papers, and several minor amendments were made (reduce information on observational cohorts and include information about facilitators and barriers to mental imagery, and additional quality appraisal tools for cross sectional studies, single case designs and case studies). Data were extracted independently for 30% articles by two members of the research team. The following were extracted: (a) study reference and year, (b) recruitment source and geographical location of study, (c) study aim and design, (d) participant information (number per group, sex and age), (e) diagnosis of intellectual disability and IQ (f) aspect of mental imagery considered and (g) main findings (see Table 1). There was an inter-rater reliability of 97%, $k = 0.94$ for data extraction.

2.6 Quality Appraisal

Quality appraisal was assessed using the relevant appraisal tool (the JBI Randomised Controlled Trials Checklist, the JBI Qualitative Studies Checklist, the JBI Checklist for Case Reports, the JBI Checklist for Quasi-Experimental Studies, the JBI Critical Appraisal Checklist for Analytical Cross-Sectional Studies and the Single Case Design Risk of Bias Tool; Reichow et al., 2018).

One additional item 'Were ethical issues considered (e.g., informed consent, approval from appropriate ethics committee, discussion of consent or best interests

decisions reported)?’ was added to all but the JBI Qualitative Studies Checklist, which already contains an item addressing ethical issues. Each item was rated according to 4 possible responses ‘yes’, ‘no’, ‘unclear’ or ‘not applicable’.

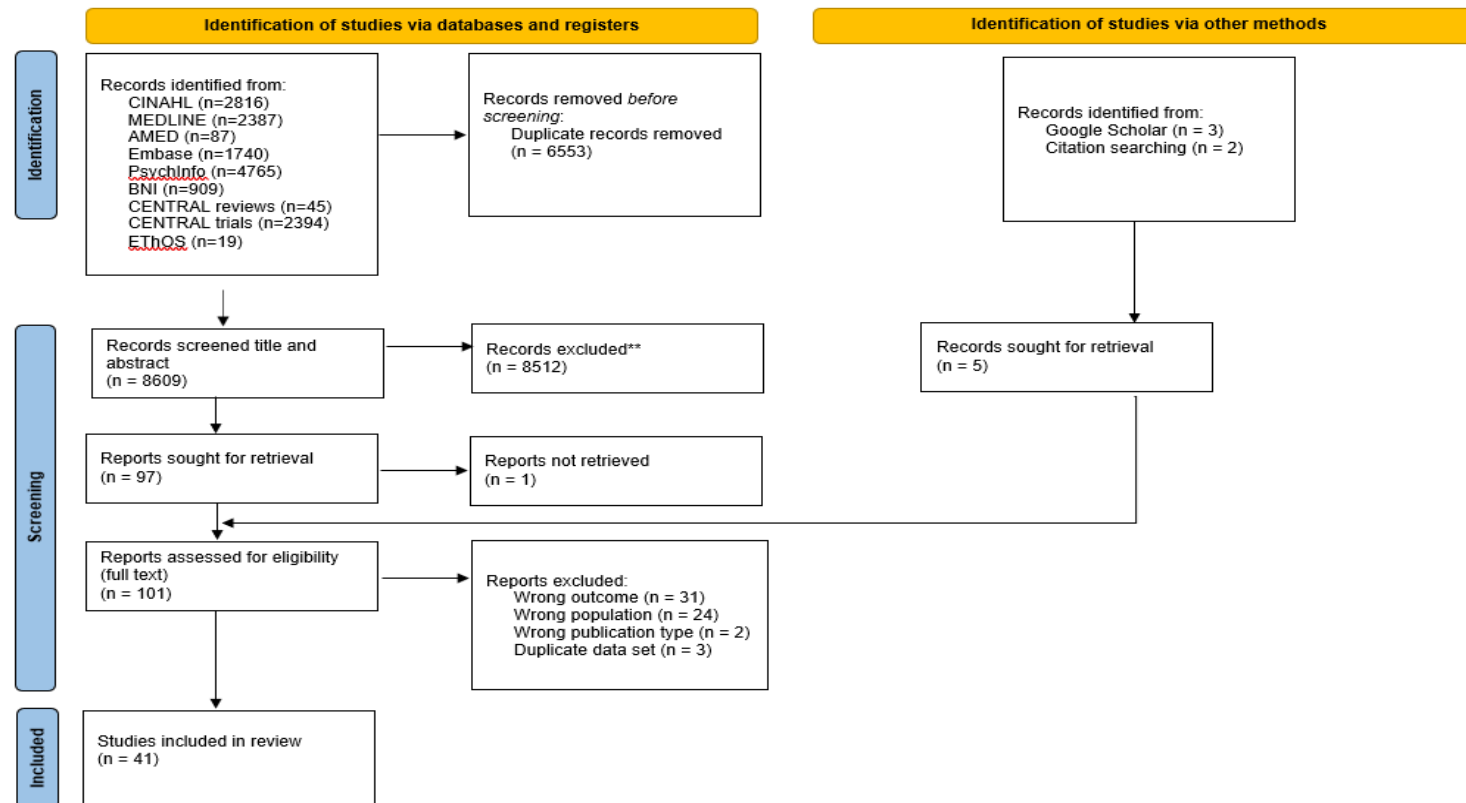
An overall risk of bias judgement, summarising the overall quality of the paper was made. Papers were given an overall ‘good’ rating if 75% or more of applicable categories were rated as ‘yes’, an overall ‘mixed’ rating if between 75 and 50% of items were rated as ‘yes’, and an overall ‘poor’ rating if less than 50% of items were rated as ‘yes’. Details of quality appraisal for each study, grouped by study design in given in Appendix 2.

Quality appraisal tools were completed independently by OH and HG for 40% of articles, resulting in an inter-rater agreement level of 97%, $k = 0.94$. All conflicted decisions were resolved through discussion, and 100% agreement was reached on all studies.

Quality appraisal was not used as a decision-making tool for inclusion in this review (Popay et al., 2006). Given the disparate range of identified papers, and the variability in quality, it was felt that important information about mental imagery in people with intellectual disabilities could be lost if papers with methodological flaws were excluded. However, the quality of papers is critically appraised within the synthesis.

Figure 1

PRISMA Flowchart to Detail Papers Identified and Excluded at Each Stage



2.7 Data Synthesis

Data was synthesised using narrative synthesis techniques (Popay et al., 2006), and the PRISMA statement (Moher et al., 2009). This approach uses words to summarise and explore data from all studies (both quantitative and qualitative) in order to address the research questions. Data synthesis was organised around Kosslyn's (1980; Kosslyn, 1994) model of mental imagery, using the four aspects of image generation, maintenance, inspection and transformation, in order to structure the synthesis. Additional studies were organised according to their focus on various therapeutic interventions, or their exploration of the phenomenology of mental imagery.

Results

The 41 included studies were conducted in ten countries, with 32% (n = 13) conducted in the USA. Other countries included the UK (n = 8), The Netherlands (n = 5), Italy (n = 5), Australia (n = 2), France (n = 2), Canada (n = 2), Japan (n = 1), Spain (n = 2) and Iran (n = 1). The number of participants in each study ranged from one to 411.

Nine studies were RCTs, 15 were quasi-experimental, four were cross-sectional, four were qualitative, eight were case reports and two used experimental single case design. In terms of the focus of the study, 28 were experimental studies examining the ability of people with ID to engage in aspects of mental imagery, and 13 reported on therapeutic interventions, of which mental imagery formed a core component (as per inclusion criteria). These included EMDR (n = 9), Imagery Rehearsal Therapy (n = 1), Relaxation Training (n = 2) and Compassion Focused Therapy (n = 1). One paper specifically investigated the phenomenology of mental images.

Table 1*Study Characteristics of Papers Included in Review*

	First author (year), Recruitment source, location	Study Aim and Design	Participants (number; sex; age in years)	ID diagnosis; IQ	Mental imagery aspect (generation, maintenance, inspection, transformation, or phenomenology or therapeutic intervention in which mental imagery is a core component)	Main findings	Quality appraisal rating
1	Barrowcliff (2015); Referred to NHS services; UK	To report on the use of EMDR for PTSD symptoms with a client with moderate-severe ID. Single case study	N=1; F; 40s	moderate-severe learning disability; No IQ given	EMDR (imagery practice to generate safe place)	Participant was able to identify safe place easily although required several weeks of imagery practice to support its ready application. Significant improvement in trauma symptoms were maintained at 12-month follow-up.	Mixed
2	Borys (1980); State residential institution; USA	Do people with ID use mental rotation and therefore show increased	N=22; NG; mean age 19.26 (SD 1.76)	“educable mentally retarded”; mean FSIQ 65	Transformation. Two mental rotation tasks; the Cone task(identifying same/ different pairs of	Participants exhibited a linear increase in their reaction time judgments as a	Mixed

		reaction times judgments with increasing angular separation between stimuli? Quasi-experimental, repeated measures design			stimuli, mental rotation task involving one stimulus being rotated 0°, 45°, 90°, 135° or 180° degrees clockwise from the upright) and the Block task (predicting the arrangement of three coloured blocks which had been rotated through 90°, 180°, 270° or 0° degrees by the examiner)	function of increasing angular separation between stimuli. ID participants were using an analogical mental rotation process to perform task.	
3	Brougham (2020); Further education colleges; Scotland UK	Can individuals with ID can generate and use a compassionate image? Qualitative, between groups.	N=31; ID group n=16; F=6 M=10; mean age 19.63 Non-ID group n=15; F=6 M= 9; mean age 21.27	WASI scores ID mean FSIQ = 59.0 Non-ID group mean FSIQ = 92.7	Generation (Generate compassionate mental image using adapted instructions, including using a storyboard provide context for the exercise, simplified language, slower pace, and forced choice and open-ended questions) Phenomenology of MI reported	Individuals with ID could generate their own compassionate image. Types of image generated were very similar in those with and without ID. People with ID required more scaffolding to prompt and use the images.	Good
4	Brown (2006); ID group recruited through agency providing services to	To explore the presence or absence of MI across different sensory modalities in	N=26; ID group n=16; F=9 M=7; mean age 43 y 8m	PPVT-R conducted with 15 ID group Mean Raw Score 80.87;	Generation and inspection (asked participants to create mental images of photos they had previously been	All non-ID and most ID participants reported MI, predominantly in the visual domain, but	Poor

	people with ID; non-ID group undergraduate students; Australia	people with and without ID. Qualitative, between groups.	(min 31 y 5 m max 70 y) Non-ID group n=10; F=5 M=5; mean age 27 y 10 m (min 18 y 8m max 50 y 1m)	Mean Age Equivalent 7 y, 1 m; ID group all had history of institutionalisation	shown across different sensory modalities and manipulate these images) Phenomenology of MI investigated	across other modalities. MI was more frequent and varied in non-ID group.	
5	Buhler (2014); Through a service agency operating under the Maryland Developmental Disabilities Administration; USA	Can EMDR be successfully used with people with ID? Multiple-baseline across participants A-B-A with follow-up design	N=6; F=3 M=3; mean age 51.6 (min 37 max 69)	WASI scores mean FSIQ = 65.5	EMDR (imagery practice to generate safe place)	EMDR can be effective for treating PTSD in people with ID.	Mixed
6	Campione (1985); ID group 7th and 8th grade students; non-ID group 4th grade students; USA	To compare ID and non-ID groups of children on tasks requiring mental imagery rotation, imposition, and subtraction. Quasi-experimental, cross sectional, between groups	N=50; ID group n=25; NG; mean age 10.4 y Non-ID group n=25; NG; mean age 9.1 y	ID group mean WISC FSIQ = 72, mean CA 14.5y, mean MA of 10.4y Non-ID group mean PPVT-R IQ = 118, mean MA of 10.7y	Transformation (mental image rotation, imposition, and subtraction tasks, based on Ravens matrices). Each item consists of three figures presented in a row. In rotation problems, the left-most figure in each row is rotated 90 ° clockwise to obtain the figure in	ID and non-ID groups were equivalent on tasks at baseline. Groups required the same amount of input to master tasks. Non-ID groups retained and generalised rules better. Both ID and non-ID groups are able to learn MI tasks.	Good

					the centre, and that figure is then rotated another 90 ° clockwise to obtain the right-most figure. In the imposition problems, the figures in the left and centre positions of each row are superimposed to obtain the figure in the right position. In the subtraction problems, the figure in the centre of each row is deleted from the figure in the left column of that row to obtain the entry in the extreme right column.		
7	Carretti (2022); participants in previous experimental studies; Italy	To analyse developmental trajectories in spatial-sequential and spatial-simultaneous working memory, based on chronological age and mental age. Cross sectional, observational	N= 411; DS group n=84; F= 46.43%; age 7-30 TD group n= 327; F = 38.84%; age 4-8	Diagnosis of Down Syndrome	Transformation (mental image rotation, imposition, and subtraction tasks, based on Ravens matrices) Maintenance (Working Memory Matrices; a matrix presented and participant has to indicate immediately after presentation all	People with DS performed better on spatial-sequential than spatial-simultaneous working memory tasks. Developmental trajectories in DS are similar to TD until about 13 years, while they are different in late adolescence and adult age	Good

					target cells on a blank matrix)		
8	Courbois (1996); Non-ID group from school; ID group from 4 specialised institutions; France	To assess imagery abilities of participants with ID on tasks requiring image generation, maintenance, inspection, and transformation (rotation). Quasi-experimental, cross sectional, between groups	N=76; Sociocultural ID group n=20; F=10 M=10; mean age 15.5 (SD 1.14) Organic ID group n=20; F=9 M=11; mean age 15.83 (SD 1.01) Non-ID group 8-year-olds n=20; F=10 M=10; mean age 8.16 (SD 0.47) Non-ID group 5-year-olds n= 16 (F=7 M=9) mean age 5.56 (SD 0.31)	Sociocultural ID group mean FSIQ = 51.65 Organic ID group mean FSIQ = 48.15 Non-ID group 8-year-olds FSIQ NG Non-ID group 5-year-olds FSIQ NG	Generation (adaption of Kosslyn, Margolis et al (1990) task; imagine an uppercase letter as it would appear on a 4 x 5 grid of cells) Maintenance (memorise a simple or complex pattern appearing on a grid maintained over short or long duration) Inspection (over short, long or no distance) Transformation (mental rotation required to judge if two stimuli were identical)	ID groups performed significantly lower than non-ID groups even when matched for mental age. Organic ID group showed specific difficulties with image maintenance, were slower to generate MIs, but faster at mental rotation than the sociocultural ID group. Aetiology of ID may impact on MI skills.	Mixed
9	Courbois (2007); NG; France	To investigate the effect of visual properties of a figure on the ability of people with ID to use mental rotation.	N=50; ID group n=16; F=8 M=8; mean age 15.92 (SD 11 m)	NG; ID group mean FSIQ = 54.5 (SD 4.37) based on WISC-III, no detectable brain lesion	Transformation (mental rotation task involving three 2-D unfamiliar shapes composed of four arms. For each shape, there was a version with a salient	ID group were able to encode and imagine rotations of unfamiliar figures. ID group did not have significantly different error rates	Good

		Quasi-experimental, cross sectional, between groups	Matched MA group n=18; F=9 M=9; mean age 8 (SD 4 m) Matched CA group n=16; F=8 M=8; mean age 16.5 (SD 4 m)		feature and a version with no salient feature)	from CA- and MA-matched groups. ID participants find mental rotation tasks more difficult when stimuli have no feature with a salient axis of elongation.	
10	de la Iglesia (2004); Children recruited from Spanish state school, early healthcare unit n=3 and Downs Syndrome Association. Adults recruited from Spanish occupational workshop; Spain	To investigate the effect on recall in a paired-associates task of different strategies (imagery, drawing and repetition) in children and adults with DS. Mixed design, Cross sectional	N=51; Child ID Group n=22; F=8 M=14; mean age 9.20 (min 7 max 12) Adult ID Group n=29; F10 M19; mean age 29.76 min 18 max 57	Child ID group (KBIT) mean IQ = 53.13 (SD 10.28), min 40 max 73 Adults mean IQ (KBIT) 43.02 (SD 5.01), min 40 max 57	Generation (to consider the impact of mental image generation in performance on immediate and delayed recall of paired-associates task)	Both adults and children with DS can follow verbal instructions to form mental images of the paired associates to be learned. In learning paired associates, most successful strategy was seeing drawings, then mental imagery, then repetition.	Mixed
11	de la Iglesia (2005); Children recruited from Spanish state school, early healthcare unit n=3 and Downs	To investigate the effect on prose recall of different memory strategies (auditory listening, mental imagery, looking at drawings) in	N=52; Child ID group n=22; F=7 M=15, mean age 9.20 (min 7 max 12) Adult ID group n=30;	Child ID group (KBIT) mean IQ = 53.13 (SD 10.28), min 40 max 73 Adults mean IQ (KBIT) 43.02 (SD 5.01), min 40 max 57	Generation (mental image generation in prose-recall task; Three prose texts were learned using colour drawings, mental imagery and auditory learning. The results for recall using	Both adults and children with DS can follow verbal instructions to form mental images of the prose to be recalled. In learning prose, most successful strategy was seeing	Good

	Syndrome Association. Adults recruited from Spanish occupational workshop; Spain	children and adults with DS. Mixed design, Cross sectional	F11 M19; mean age 29.5 (min 18 max 57)		the first two strategies were then compared to those for auditory learning)	drawings, then mental imagery, then listening to story. Pattern of results the same for immediate and delayed recall	
12	Dilly (2014); Secure forensic hospital; UK	To describe the use of EMDR with a person with mild ID and complex presentation in a forensic setting. Single case study	N=1; M=1; age 25	Diagnosis of intellectual disability	EMDR safe place visualisation technique developed using multi-sensory prompts (a selection of photographs and a scented pine cone))	A “safe place visualisation technique” was developed to manage participant’s arousal and used in every session. Symptom reduction in re-experiencing, avoidance and arousal were maintained at one- and six-month follow-up.	Good
13	Di Nuovo (2018); rehabilitation centre for people with ID; Italy	Can MI moderate the effect of cognitive components on the degree of mental deterioration in adults with ID? Cross sectional, observational	N=40; F13 M27; mean age 35.70 (SD 11.89), min 16 max 64	Mild or moderate ID	Generation, maintenance, inspection, transformation (used Mental Imagery Test (MIT); DiNuovo, Castellano & Guarnera, 2014). The MIT comprises 8 tasks; Visualizing letters (imagine uppercase letters and deciding whether they contain curved parts); Brooks ‘F’ Test (to	A significant relationship found between MoCA and all factors of WAIS-IV, except for Processing Speed. A significant relationship found between MIT score and cognitive domains of the WAIS-IV. A strong correlation shown between MoCA score and	Poor

					mentally examine the contour of a letter F; Clock (imagine what hour a clock reflected in the mirror indicates); Cube (visualize a large cube made up of many small cubes, and identify how many corner and middle external faces it shows); Subtraction of parts (to subtract in imagination parts from figures); Map (to mentally explore distances between features on a map); Imagined paths (to imagine, according to sequential indications from the examiner, the paths of a dot moving in the space); Representation of shapes of objects (to visualize objects of different shapes, discriminating the wider from the higher)	MIT score ($r=.70$, $p<.01$).	
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14	Doerr (2021); participants in previous experimental studies; Italy	To analyse developmental trajectories in spatial visualization and mental rotation, based on chronological age and mental age. Cross sectional, observational	N= 87; F40 M47; mean age 19.46 (SD 9.57) min 7.75 max 53.25	Diagnosis of Down Syndrome	Transformation (mental rotation task Ghost Picture test) Two similar silhouettes are presented beneath the target figure, but only one of them is identical to the target but is rotated, while the other is a mirror image of the target figure. Participants are asked to choose the figure that matches the target silhouette.	Mental rotation performance increased after 5 years which continued until 14 years and then decreased. Developmental trajectories in mental rotation depended on the rotation degree. Development level, not chronological age better describes changes in spatial visualization and mental rotation of individuals with DS.	Mixed
15	Gibson (1995); Regular and resource elementary school classrooms in 3 rural schools; USA	To compare visual imagery strategies on learning in children with ID and groups of children matched for MA and CA. Randomised Controlled trial	N=166; ID group n=44; (F18 M 26); mean age 12.04 (SD 0.46), min 10.67 max 13.01 Matched MA group n=62; NG; mean age 7.02 (SD 0.48) min 6.10 max 7.92	Mild ID; IQ mean 62.61 (SD 5.21), min 52 max 70	Generation (generate image of pictures to illustrate a story). Children were either read a story (control condition), shown pictures accompanying a story (imposed imagery) or asked to generate their own images to accompany the story (induced imagery).	ID group did not recall as much information as MA matched group. Using pictures improved recall for both ID children and TD children of equivalent MA, suggesting strategic support of imagery process benefits ID group. However, children with ID scored as	Mixed

			Matched CA group n=60; NG; mean age 11.55 (SD 0.36) min 11.00 max 12.33			poorly in the condition in which they were instructed to create mental images as the control condition. Conclude ID group are not deficient in mental imagery but require this to be supported, as they may not do this spontaneously or when simply instructed to do so.	
16	Gordon (1994); Elementary school; USA	To compare the ability of children with ID and those matched for MA to remember and discriminate real from imagined events, both immediately and over a delay. Quasi-experimental, cross sectional, between groups	N= 46; ID group n=23; (F11 M12); mean age 10.3 (min 8.1 max 13.0) Non-ID group n=23; (F8 M15); mean age 6y 5m (min 6.1 max 6.8)	ID group mean PPVT-R scores = 57.35 Non-ID group mean PPVT-R scores = 95.96	Generation and inspection (children were asked to engage in and imagine themselves engaging in interactive activities with experimenter)	Both ID and non-ID groups performed well on this complex task of remembering and discriminating activities performed and imagined. Patterns of responses were similar for both groups. Performed activities were remembered significantly better than imagined activities by both ID and non-ID group.	Good

						ID group were more likely to misclassify activity as performed or imagined when questioned later.	
17	Hardiman (2018); referred to NHS services; UK	To conduct a mixed-methods investigation of the effects of a CFT intervention in people with ID. Mixed methods	N=3; (F2 M1); age 31,47,48 (mean age 42)	Mild-moderate ID "based on clinical judgement and recent BPS guidelines"	Compassion Focused Therapy (imagery practice to generate safe place, practiced weekly in therapy sessions and clients encouraged to practice between sessions)	All participants reported reliable reductions in anxiety but remained above clinical cut-off for diagnosis. Self-compassion improved for all participants, with continued improvement at follow-up for two participants.	Good
18	Hart (2014); referred to NHS services; UK	To evaluate a new service providing relaxation training over a 12-week intervention. Case study	N=15; NG; NG	Mild-moderate ID	Relaxation training (generate guided imagery using scripts tailored to each individual)	Results showed a positive downward trend in anxiety. Results from the pulse oximeter readings were universally positive, showing a reduction in heart rate after using relaxation techniques.	Poor
19	Hemayattalab (2010); mentally retarded school; Tehran	To investigate the effects of mental imagery and physical practice on the learning of	N=40; NG; age min 12 max 15	"Trainable mentally retarded students"	Generation (mentally practice throwing basketball). Participants randomly assigned to one of	In people with ID MI practice is more effective than no practice, but less effective than	Poor

		a perceptual-motor task (basketball free throw) in adolescents with ID. Randomised Controlled Trial across 5 conditions (physical practice only, mental practice only, physical practice followed by mental practice, mental practice followed by physical practice, and no imagery–no physical practice)			five conditions (physical practice, mental practice, physical practice followed by mental practice, mental practice followed by physical practice, and no practice)	physical practice. A combination of mental practice and physical practice is more effective than only physical practice.	
20	Hinnell (2004); ID group recruited through Downs Syndrome organisation, non-ID group through schools; Canada	To ascertain if people with DS with a mental age greater than 5 years can perform spatial mental transformations. Quasi-experimental,	N=16; ID group n=7; F4 M3; mean age 29.8 (SD 5.4), min 22 max 26 Non-ID group n=9; F5 M4; mean age	ID group consisted of those with Down Syndrome	Transformation (mental rotation task). Participants viewed an upper case 'F' or a mirror image of an 'F' presented at one of eight different orientations. Participants determined whether the letter was	Individuals with Down Syndrome performed mental rotation tasks well above chance level, indicating that the skill set does develop and does exist, although it may be compromised	Good

		cross sectional, between groups	7.2 (SD 1.2), min 6 max 9		reversed or non- reversed.	compared to TD individuals.	
21	Ikeda (2014); Special schools and mainstream elementary schools; Japan	To examine features of inhibitory control in children with ID, children with ID and ASD, and mental-age matched TD children. Quasi- experimental, cross sectional, between groups.	N=41; ID alone group n=11; F7 M4; mean 15.83 (SD 1.68) min 13.17 max 18.08 ID + ASD group n= 9; F3 M6; mean age 15.44 (SD 1.38) min 12.83 max 17.08 TD group n=21 F10 M11; mean age 8.46 (SD 0.52) min 7.50 max 9.25	ID diagnosis made by psychiatrist or paediatrician; criteria chronological age under 18, IQ under 70	Inspection (Real Animal Size Test and Pictorial Animal Size Test). Participants are presented with pictures of large (e.g. elephant) or small animals (e.g. frog) printed as big or small images mismatched with the animal's real size.	ID alone group showed impaired inhibitory control compared to TD group. The ID group did not differ from the TD or ID+ ASD groups in terms of error rates. Suggests ID participants were able to successfully complete the MI aspect of the task.	Good
22	Jens (1990); schools; Australia	How well do children with and without ID discriminate events in which they actually participated versus those for which they only imagined	N=54; ID group n=24; F5 M19; mean age 10 y 8 m (Min 7y 5m to max 16y 7m)	ID group mean FSIQ = 63.25 (min 47 max 76.5)	Generation (imagine participating in an activity). Children were asked to perform a series of tasks or only imagine performing them. They then remembered which had been performed	ID group and age matched TD group were equally good at remembering activities performed or imagined both at immediate recall and 8-week delay.	Mixed

		participating, both at an initial interview and after an 8-week delay? Randomised controlled trial	TD group n=30; NG; average age of 6y 5m (min 5y 7m max 7y 0m)		and which imagined at immediate interview and after 8-week delay.		
23	Karatzias (2019); referred to NHS ID services; UK	To compare EMDR plus SC versus SC alone for PTSD in adults with ID. Randomized controlled feasibility trial with qualitative process evaluation	N=29; EMDR+SC n= 15; F9 M6; mean age 42 (SD 11.3) SC n=14; F9 M5; mean age 42 (SD 12.1)	Diagnosis of mild-to-moderate ID EMDR+SC mild ID n=13 moderate ID n = 2 SC mild ID n= 11 moderate ID n=3	EMDR (protocol details assessing components of distressing memory, including an image, and the current emotional and physiological components of the image)	EMDR+SC resulted in lower levels of anxiety and more participants being PTSD symptom free post treatment. EMDR+SC showed higher dropout rates.	Good
24	Kwong (1994); inner city school; Canada	To explore the awareness and use of various memory strategies in adolescents with ID compared with those without ID. Quasi-experimental, cross sectional, between groups.	N=19; ID group n=9; F6 M3; mean age 174.7 m (min 164m max 184m); TD group n=10; F9 M1; mean age 174.7 m (min 105m to 133m)	Mild ID ID group mean WISC-R FSIQ score = 68.8 (min 60 max 76)	Generation (assessing visual imagery as memory strategy). Compared the frequency and type of different memory strategies used by participants.	ID participants preferred maintenance rehearsal and visual imagery as memory strategies. TD participants used a wider range of memory strategies and more complex strategies. ID ppts reported using MI spontaneously and consistently	Good

						regardless of nature of the task. They used elaborative rehearsal to a less extent and seldom used mnemonics.	
25	Leevers (1998); from mainstream nursery, ID school and centres for children with autism; UK	To test whether children with autism display an inability to imagine impossible entities when the task demands are minimal. Compared children with autism with children with moderate ID and TD 4-year olds. Quasi-experimental, cross sectional, between groups.	N=48; ASD group n=16; F3 M13, mean age 11y2m (SD 24.8), min 7y 9m max 15y 2m ID group n=16; F6 M10, mean age 11y7m (SD 16.5) min 9y 11m max 14y 4m TD group n=16; F10 M6; mean age 4y 5m (SD 4.2) min 4y 0m max 4y 11m	Moderate ID verbal mental age (TROG) 4-6 years exactly	Inspection (picture completion using drawing or colouring to complete pictures of real and impossible animals)	Children in all groups able to choose the correct pattern to make a picture look real if impossible, and also complete pictures to make them real or impossible. No difference between groups - ID group as competent as other groups on tasks.	Good
26	Meneghetti (2018); day centres for people with DS and kindergartens; Italy	To explore mental rotation ability in individuals with DS and compared them with a group of TD children	N=96; DS group n=48; F17 M31; mean age 169.33 m (SD 41.03)	Down Syndrome diagnosis	Transformation (mental rotation task; Ghost Picture test) Two similar silhouettes are presented beneath the target figure, but	DS participants have worse mental rotation performance than TD children of comparable mental age, and are influenced differently	Good

		matched on mental age. Quasi-experimental, cross sectional, between groups.	TD group n=48; F19 M29; mean age 66.83 m (SD 3.47)		only one of them is identical to the target but is rotated, while the other is a mirror image of the target figure. Participants are asked to choose the figure that matches the target silhouette.	by angular disparity: for items rotated by 180°, DS participants were unable to perform above chance	
27	Mevisen (a) (2011); referred by mental health professional; The Netherlands	To investigate the applicability of EMDR in 4 people with mild ID, suffering from PTSD. Case study	N=2*; F1 M1; Age 32 and 53	Mild ID and moderate-mild ID	EMDR intervention	In all cases PTSD symptoms decreased and the gains were maintained at 13-28 months follow-up. In addition, depressive symptoms and physical complaints subsided, and social and adaptive skills improved. EMDR has potential applicability for people with mild ID.	Good
28	Mevisen (b) (2011); referred by mental health professional; The Netherlands	To assess the applicability of EMDR in two clients with moderate ID, serious behavioural problems, and histories of	N=1*; M1; 'middle aged'	Moderate ID WPPSI-R; average developmental level 4.9 years	EMDR intervention	PTSD-like symptoms decreased in only 5 sessions. Gains were maintained at 10 months follow-up. EMDR is a potentially applicable psychotherapeutic	Good

		negative life events. Case study				treatment method for clients with ID, even those with substantially limited verbal capacities	
29	Mevissen (2012); referred for outpatient treatment; The Netherlands	To assess the applicability of EMDR for psychological trauma in people with severe ID. Case study	N=3*; F2 M1; aged 10, 10 and 49	Severe ID	EMDR intervention	In all cases PTSD symptoms decreased, with gains maintained at 15.5 months to 2.5 years. Depressive symptoms and physical complaints diminished, and social and adaptive skills improved. EMDR seems to be an applicable treatment method for clients with severe ID. Reduction and maintenance of PTSD symptoms in individuals with severe ID appears to be both desirable and obtainable	Good
30	Mevissen (2017); referred to child and adolescent psychiatry services; The Netherlands	To explore the effectiveness of EMDR therapy for PTSD in persons with mild to borderline ID. Non-concurrent,	N=2; F1 M1; Age 10 and 18	Mild ID (FSIQ of 66 and 67)	EMDR intervention	For both participants PTSD symptoms decreased with EMDR treatment. Both no longer met PTSD criteria at post-treatment, and at 6-week follow-up.	Mixed

		multiple baseline, across subjects' design				EMDR can be effective treatment for PTSD in children and adolescents with mild ID.	
31	Poretta (1995); integrated schools; USA	To examine the effect of imagery practice in conjunction with physical practice on the performance of anticipating coincidence (striking) by adolescents with mild ID. Randomised Controlled Trial	N=32; F17 M15; mean age 15y 1m (min 13 y 1m max 17y 8m)	Mild ID (mean IQ = 66; range 56-75)	Generation of mental imagery across modality (imagine swinging baseball bat). Participants randomly assigned to a physical practice plus imagery practice group or physical practice only group.	Imagery practice in combination with physical practice seems to facilitate performance on a gross motor coincident timing task when compared to physical practice alone. All participants could use mental imagery and describe this to researcher.	Mixed
32	Rickard (1984); activity centre for mentally retarded; USA	To investigate how people with ID and varying levels of cognitive functioning respond to 4 different types of relaxation training. Quasi-experimental, cross sectional, between groups.	N=20; Group 1 n=5; NG; mean age 33.4 (SD 13.63) Group 2 n=5; NG; 23.0 (SD 8.75) Group 3 n=5; NG; 61.4 (SD 4.77) Group 4 n=5; NG; 44.6 (SD 5.41)	Mean IQ Group 1 = 93.2 (SD 5.54) Group 2 = 76.6 (SD 2.61) Group 3 = 61.4 (SD 4.77) Group 4 = 44.6 (SD 5.41)	Relaxation Training (visual image relaxation exercise with verbal instructions)	All participants (except 2) successfully engaged with visualising relaxation images. Apart from lowest IQ group, all groups engaged with every type of relaxation exercise. Participants in lowest IQ group could follow	Poor

						relaxation exercises but at a lower level than other groups	
33	Rodenburg (2009); Inpatient epilepsy service; The Netherlands	To report a case study into effects of EMDR on trauma symptoms in adolescent with mild ID and epilepsy. Case study	N=1; M1; 18	WAIS III FSIQ 67-77	EMDR (imagery practice to generate safe place)	Over 5 EMDR sessions a significant positive change in trauma symptoms was observed with PTSD symptoms improved to non-clinical levels. Suggests EMDR is effective for treating trauma symptoms in people with mild ID and epilepsy.	Good
34	Roskos-Ewoldsen (2006); high schools and university students; USA	To investigate whether participants with ID scan more slowly, at the same rate, or faster than participants without ID. Quasi-experimental, cross sectional, between groups.	N=32; ID group n=15; F=8 M=7; mean age 17.64 (SD 5.98) min 16.17 max 20.5 Non-ID group n=17; F10 M7; mean age 19.84 (SD 1.95) min 18.17 max 24.33	ID group mean IQ = 57.13 (SD 11.60) min 40 max 74 Non-ID group NG	Inspection (involving learning the location of five landmarks on a map and scanning between these)	ID group needed more trials to learn the landmark locations and had generally slower scan times. ID and non-ID groups were identical in rate of scanning for both perception and imagery conditions. People with ID have no particular deficit in image inspection.	Good
35	Screws (1997); Middle school; USA	To examine the efficacy of using MI in developing skill on	N=30; NG; mean 12.5 (min 11 max 13)	Mild ID WISC-R FSIQ = 50-70	Generation (imagine completing a motor task). Participants randomly assigned to	Physical practice significantly improved	Mixed

		motorically oriented task and cognitively oriented task in middle school children with mild ID. Randomised Control Trial			a physical, imagery or no-practice control group.	performance on both tasks. Imagery practice also enhanced motor performance on both peg board (cognitively oriented task) and pursuit rotor (motorically oriented task) although only statistically significant for peg board task. All participants could use MI practice to facilitate motor task performance.	
36	Stenfert Kroese (2006); referred to NHS ID services; UK	To illustrate the application of an adapted form of imagery rehearsal therapy to adults with ID. Case study	N=2; F2; age 18y and 24y	Mild ID; Both participants had IQ 55-69	Imagery Rehearsal Therapy (using image generation to replace distressing dreams with different endings)	For both participants, nightmares ceased within 6 weeks and maintained at 6 months follow up. Imagery rehearsal therapy is suitable for people with ID.	Good
37	Surburg (1991); high school; USA	To explore the use of imagery practice to facilitate the preparation of adolescents with mild ID to perform a motor task.	N=63; sex NG ID group n=32; mean age 16.5 (SD = 1.31) min 14 max 18	Mild ID IQs on the Woodcock-Johnson Psycho-Educational Battery or Stanford-Binet	Generation (imagery practice in completing a button press, reaction time task)	Imagery practice was effective with subjects with and without mental retardation. Imagery practice facilitated performance of	Mixed

		Randomised Controlled Trial	TD group n=32 Mean age 16.3 (SD = 1.51) min 14 max 18	Intelligence Scale ranged from 49 to 70 (mean = 65, SD = 6.21); classification based on multiple criteria including IQ, scores on an adaptive behaviour instrument, and grade attainment.		subjects in the group who experienced catch trials but also used imagery practice. For adolescents with mild ID who manifest marked preparatory difficulties as related to motor skill execution, imagery practice is a strategy that should be considered to enhance the skill.	
38	Surburg (1995); integrated schools; USA	To examine the role of imagery practice as supplementary practice in performance of throwing task in people with ID. Randomised Controlled Trial	N=40 Indiana group n=20 F11 M9; mean age 16y 6m, (SD 11.9m), min 15y 0m, max 18y 5m Ohio group n=20; F11 M9; mean age 14y 7m (SD 1y 4m), min 13y 2m max 17y 9m	Intelligence based on Stanford-Binet test and certain behavioural characteristics. Indiana group mean IQ = 70.5 (SD 6.58), min 59 max 81 Ohio group mean IQ = 66 (SD 6.64), min 53 max 72	Generation (compared imagery and physical practice with only physical practice on a throwing task)	Groups using imagery as well as physical practice showed superior performance to non-imagery groups. Imagery practice improves motor performance of students with mild ID.	Mixed
39	Uecker (1994); mainstream and self-contained learning	To compare TD children, LD children (not in the ID range),	N=56, Control Group n=22; F12 M10;	DS group mean PPVT-R age of 3y, 1m (SD = 1.1)	Transformation (Participants were required to use mental rotation to	Control group were quickest in performing the mental rotation task,	Good

	disabled classrooms; USA	and DS children on a mental rotation task that examines their use of imaginal spatial processes. Quasi-experimental, cross sectional, between groups	mean age 9y 2m (SD 1.4), LD Group n=24; F7 M17; mean age 10y 3m (SD = 1.1), DS Group n=10; F2 M8; mean age 8y 4m (SD = 1.9)		determine on what side the stimulus of a stick figure was holding a ball))	followed by LD group and then DS group. DS group were significantly less accurate than control and LD groups. Mental rotation skill was arrested in the DS population.	
40	Vicari (2006); children's hospital; Italy	To investigate the possible dissociation between visual-object and visual-spatial working memory in individuals with Williams syndrome and Down syndrome. Quasi-experimental, cross sectional, between groups	N=66; WS group n=15; F5 M10; 19y 8m (SD 6y 1m) WS comparison group n=15; F8 M7; 6 y 10m (SD 10m) DS group n=18; F7 M11; 15 y 10 m (SD 5y 8m) DS comparison group m=18; F8 M10; 5 y 1m (SD 7m)	DS group mean mental age 5y 2m (SD 8m)	Inspection (Mental Colour Comparison Test modified (De Vreese 1991) stating whether two typically coloured objects are the same, and Animal tails (Farah et al. 1988) (judging which of two stated animals has a longer tail) Transformation (Stick Test; Carlesimo et al. 2001; participants use mental rotation to determine which of four similarly shaped stimuli would match a rotation of the original stimulus) and Spatial Rotation Test;	Visual-object and visual-spatial working memory may be differentially compromised in people with ID underlain by different genetic syndromes. Reduced visual, but relatively preserved, spatial abilities were shown in perceptual and imagery tasks in individuals with DS.	Good

					participants create a visual image by mentally rotating geometric drawings and match with one of six alternatives).		
41	Wilen (1982); special educational school classes; USA	To investigate the use of imagery and verbal elaboration strategies to facilitate the paired-associate learning of adolescents with ID. Randomised controlled trial	N=48; F24 M24; mean age 19 (min 17y max 21y)	Moderate ID "Mentally Retarded Trainable Level" based on a comprehensive psychological evaluation administered by a certified school psychologist. FSIQ under 55	Generation (assessing visual imagery, verbal elaboration and a combined imagery-verbal elaboration condition as memory strategies)	Participants paired-associate performance can be substantially improved through the use of cognitive strategies (imagery, verbal elaboration or a combined imagery-verbal elaboration condition) compared with rote learning. No significant difference found between the 3 cognitive strategies.	Mixed

NHS = National Health Service; UK = United Kingdom; USA = United States of America; PTSD = Post Traumatic Stress Disorder; IQ = Intelligence Quotient; FSIQ = Full Scale Intelligence Quotient; ID = Intellectual disability; MI = mental imagery; NG = not given; PPVT-R = Peabody Picture Vocabulary Test-Revised; WISC = Weschler Intelligence Scale for Children; WAIS = Weschler Intelligence Scale for Children; y = years; m = months; MA = mental age; CA = chronological age; KBIT = Kaufman brief intelligence test; TD = typically developing; SC = standard care; EMDR = Eye Movement Desensitisation and Reprocessing; DS = Down Syndrome; LD = learning disability; CCAT = Criteria Cognitive Aptitude Test; WPSSI-R = Wechsler Preschool and Primary Scale of Intelligence; MoCA = Montreal Cognitive Assessment; WS = Williams Syndrome; RT = reaction times; CFT = Compassion Focused Therapy; BPS = British Psychological Society; WASI = Wechsler Abbreviated Scale of Intelligence; KBIT = Kaufman Brief Intelligence Test; ASD = Autism Spectrum Disorder; SC = Standard Care; TROG = Test for Reception of Grammar; WPPSI-R = Wechsler Preschool and Primary Scale of Intelligence – Revised;

SD = Standard Deviation. * Papers originally included additional participants but only the results of those not diagnosed with ASD are reported here.

Four studies did not clarify that a diagnosis of intellectual disability was given to participants, instead making mention of other categorisations such as ‘mentally retarded trainable level’, although it was clear from the source that participants met inclusion criteria in terms of having an intellectual disability. Ten studies did not report the severity of the participants' intellectual disability (i.e., mild, moderate, severe etc). Sixteen studies did not report a Full-Scale IQ for participants.

Fifteen studies contained adult participants (aged 18 years or older), and 17 studies focused on children. Nine studies contained both child and adult participants. Three studies did not report participants' age, and three only provided mean ages for groups of participants. Nine studies did not report the sex for either all (n = 8) or a subgroup (n = 1) of participants.

Participants were recruited from a variety of settings, with 17 studies recruiting from schools or colleges, 14 from healthcare settings (including five from the United Kingdom's National Health Services), and a range of other settings such as day centres (n = 3), state institutions (n = 2), agencies providing services to people with intellectual disabilities (n = 3), and from previous experimental studies (n = 2). One study did not state their recruitment sources, and some studies recruited from multiple different sources.

3.1 What Do We Understand About the Abilities of People with Intellectual Disabilities to Engage with Mental Imagery (the Generation, Maintenance, Inspection, and Transformation of Mental Images)?

Generation

Fifteen studies specifically investigated the ability of people with intellectual disabilities to generate a mental image. Of these three were rated as good quality

(Brougham et al., 2020; Gordon et al., 1994; Kwong, 1994). Ten were rated as mixed quality (Courbois, 1996; de la Iglesia et al., 2005; de la Iglesia et al., 2004; Gibson et al., 1995; Jens et al., 1990; Porretta & Surburg, 1995; Screws & Surburg, 1997; Surburg, 1991; Surburg et al., 1995 and Wilen, 1982). Three were rated as poor quality (Brown & Bullitis, 2006; Di Nuovo et al., 2018; Hemayattalab & Movahedi, 2010).

Generating Random Patterns

Two studies looked at participants' ability to generate visual images of random patterns. Screws and Surburg (1997) conducted a RCT in which participants completed a peg board test, and examined the effects of physical practice, mental imagery practice, and no practice on performance. A lack of clarity around whether allocation to groups was concealed, as well as similarity of groups at baseline, and blinding (for participants, those delivering treatment and outcome assessors) mean the validity of results is uncertain. Whilst physical practice significantly improved performance, imagery practice also significantly enhanced motor performance, suggesting participants could generate images to complete mental imagery practice of the task. Courbois (1996) conducted a generally robust, quasi experimental study investigating all four aspects of mental imagery, although it was unclear whether participants included in comparisons were similar which threatens the internal validity of the study as differences between groups may be due to selection bias. They concluded that adolescents with intellectual disabilities found complex images more difficult to generate and have poorer mental image generation skills than mental age matched typically developing children. Courbois (1996) adapted the Kosslyn et al. (1990) paradigm for participants who cannot read. They excluded three participants who were unable to learn the task (one of whom had an intellectual disability) suggesting that

people with intellectual disabilities were as able to complete the mental imagery generation task as their mental age matched, typically developing peers. Low error rates were seen across all groups.

Generating Meaningful Stimuli

Three studies asked participants to create images of meaningful stimuli. Brougham et al. (2020) reported in a well-designed qualitative study that people with and without intellectual disabilities performed similarly on a task to generate a compassionate image. This paper clearly linked the research question with an appropriate qualitative methodology and method of data analysis, although the researchers' cultural or theoretical position was not stated. Whilst participants with intellectual disabilities required additional prompts and scaffolding to generate and use their images, these images were very similar to those generated by participants without intellectual disabilities. Brown and Bullitis (2006) asked participants to create mental images of photos they had previously been shown and manipulate these images. Participants with intellectual disabilities seemed less familiar with the idea of mental imagery than those in the comparison group, and provided more concrete descriptions of the imagery, although with considerable individual variation. Eighty-seven percent of participants with intellectual disability could spontaneously describe a mental image they generated, and the remaining participants could also do this but required prompting. Di Nuovo et al. (2018) used the Mental Imagery Test (MIT) which contained two subtests focused on image generation, Visualizing Letters and Clock. This study had various quality issues including no clear inclusion criteria, little detail about the participants and setting of the study, no confounding factors considered or managed, and a lack of clarity over whether the exposure was measured in a reliable and valid

way. Unfortunately, results were not provided for individual subtests, but the authors reported participants with intellectual disabilities had no difficulties engaging with the MIT.

Image Generation to Enhance Memory

Several studies looked at participants' ability to generate mental image as a memory strategy. Kwong (1994) reported a high quality, methodologically sound study into the types of memory strategies used by people with and without intellectual disability. Participants with intellectual disability preferred maintenance rehearsal and visual imagery as memory strategies. Typically developing participants used a wider range of memory strategies and more complex strategies. Participants with intellectual disabilities reported using mental imagery spontaneously and consistently regardless of the nature of the task. They used elaborative rehearsal to a lesser extent and seldom used mnemonics. de la Iglesia et al. (2004) examined performance on a paired-associated test and reported that both adults and children with Down syndrome can follow verbal instructions to form mental images when learning this task. They found that whilst generating mental images was more effective than repetition as a memory strategy, it was less helpful than seeing actual drawings of images. A similar study by the same authors (de la Iglesia et al., 2005) compared similar groups of children and adults with Down syndrome on a prose recall task. They found that again, the most helpful memory strategy was seeing actual drawings of images related to the prose, followed by generating a mental image of the prose, and lastly by attentive listening to the content of the prose. Both of these studies would have been strengthened by including a comparison group and taking multiple measures of outcomes before and after intervention.

Wilén (1982) also used a paired-associates test to examine the effect three different memory strategies (mental imagery, verbal elaboration, or a combined imagery-verbal elaboration condition) compared to rote learning in a RCT design. Performance was substantially improved with cognitive strategies compared with rote learning, although no significant difference was found between the three different cognitive strategies. A threat to the validity of this otherwise well-designed study is the lack of blinding for participants, those delivering the intervention, and outcome assessors. Gibson et al. (1995) compared groups of children with intellectual disabilities with those matched for mental age and chronological age on conditions which included being shown pictures illustrating a story (imposed imagery), a condition in which children were instructed to imagine such pictures (induced imagery), and a control condition. Whilst the imposed imagery condition increased recall for both groups, the induced imagery results were not significantly different from control condition for children with intellectual disabilities. This indicated that simply being given an instruction to generate mental images may have been insufficient, and that children with intellectual disabilities require support in the form of scaffolding or detailed instructions and practice to generate mental images. The instructions for participants in the induced imagery condition were very basic and lacked any detail as to how mental imagery could be generated. There were no steps included to help children practice mental imagery, to check they understood the instructions, or to assess at the end of the experiment whether they had been able to generate mental images. Therefore, this, along with a lack of clarity around blinding for participants, and failure to blind those delivering the intervention or assessing outcomes detracted from this otherwise well-designed RCT.

7.1.1.4. Image Generation to Enhance Motor Skills

A number of studies used a motor skill task to investigate whether participants could generate a mental image of practicing this skill in order to enhance performance. Hemayattalab and Movahedi (2010) reported that all participants were able to generate mental images of a basketball free throw and that mental imagery practice improved scores compared to no practice (although it was less effective than physical practice). Methodological flaws in this RCT included lack of blinding, unclear whether allocation to groups was concealed, and lack of clarity about the appropriateness of the statistics (given that four experimental conditions as well as a control condition were included with a relatively small number of participants). Poretta and Surburg et al. (1995) reported that all participants could use mental imagery to practice a motor skill and describe this to researchers. Imagery practice in combination with physical practice facilitated performance on a gross motor coincident timing task when compared to physical practice alone. A lack of blinding threatened the internal validity of this study. Screws and Surburg (1997) found that all participants could generate a mental image to practice a motor pursuit task. Whilst physical practice significantly improved performance on the motor pursuit tasks, imagery practice also significantly enhanced motor performance, although to a lesser extent. Surburg (1991) found mental imagery practice was effective for all subjects in improving motor skill performance on a response-type task that included reaction time and movement time components. Methodological issues with a lack of blinding and clarity around whether allocation to groups was concealed, and if groups were similar at baseline were present in this study. These issues were also present in the study by Surburg et al. (1995), who compared imagery and physical practice with only physical practice on a throwing task. They found

that all participants had engaged with the imagery component and could describe this to researchers. Imagery practice resulted in improved performance compared to physical practice alone.

7.1.2. Maintenance

Only three studies specifically examined participants' abilities to maintain a mental image. Carretti et al., (2022) was rated as a good quality paper, Courbois (1996) was rated as mixed quality and Di Nuovo et al. (2018) was rated poor quality.

Carretti et al. (2022) conducted a cross-sectional study comparing a large sample of people with Down Syndrome and typically developing children on tasks assessing aspects of visual working memory. This included the Working Memory Matrices which required participants to observe a series of matrices, and a number of target cells are presented in each matrix (either sequentially or simultaneously). Participants then recall the target cells on a blank matrix. Whilst performance is better in both people with Down Syndrome and control groups for spatial-sequential than spatial-simultaneous working memory tasks, both tasks clearly require image maintenance. This paper did not directly compare the performance of the two groups due to differences in the size and mean developmental level of the group with Down Syndrome and the typically developing control group, Courbois (1996) conducted a robust, quasi-experimental study, in which participants memorised a pattern that appeared on a grid. Conditions varied in the complexity of the pattern (simple or complex) and retention duration (long or short). People with intellectual disabilities performed worse on this task than mental age matched typically developing children, with people with sociocultural causes of intellectual disability (defined as being from a

very low socioeconomic status background, as well as having other siblings in the family home with intellectual disabilities) performing better than those with organic cause of intellectual disability (defined as receiving no psychotropic medication and having no documented brain lesions). Such definitions of intellectual disability are controversial and not in accordance with diagnostic criteria. Complex patterns were more poorly recalled than simple patterns, although there was no effect of retention delay, suggesting the image refreshing process of people with intellectual disabilities is relatively efficient. Di Nuovo et al. (2018) included the Imagined Paths test. Unfortunately, no further information is provided about performance in this task, although it appears participants with intellectual disability were able to complete this task.

7.1.3. Inspection

Eight studies specifically examined the abilities of participants to inspect a mental image, five of which were rated as good quality (Gordon et al., 1994; Ikeda et al., 2014; Leivers & Harris, 1998; Roskos-Ewoldsen et al., 2006 and Vicari et al., 2006), two as mixed quality (Courbois, 1996; Jens et al., 1990), and one as poor quality (Di Nuovo et al., 2018). Tasks to assess mental image inspection were variable in nature.

7.1.3.1. Motor-Based

Two studies asked participants to inspect a mental image to determine if it was a real memory or an image of something they had only imagined. Gordon et al. (1994) conducted a very high quality, quasi-experimental study and found that participants with and without intellectual disability performed well on a complex task of remembering and discriminating activities performed and imagined, both at immediate

recall and 6-week delay. Patterns of responses were similar for both groups. Jens et al. (1990) used a similar task in a RCT design and again found that participants with intellectual disabilities and a chronologically age matched group of typically developing children were equally good at remembering activities performed or imagined both at immediate recall and 8-week delay. However, issues with allocation to group being concealed, and a lack of blinding posed a threat to the internal validity of this study.

7.1.3.2. Object-Based

Within several studies, participants were asked to inspect images based on objects. Ikeda et al. (2014) used well-established measures of image inspection (Real Animal Size Test and Pictorial Animal Size Test) to compare children with intellectual disabilities and typically developing children and autistic children with intellectual disabilities. Whilst children with intellectual disability showed less inhibitory control than other groups, error rates were similar for all groups. The results from this methodologically sound study suggested children with intellectual disabilities were able to successfully complete the mental imagery aspects of these tasks. Leevers and Harris (1998) reported a good quality, robust study in which children with and without intellectual disabilities completed pictures with patterns to make them look real or 'impossible' (e.g., complete a picture of a zebra with stripes or spots). They found children with intellectual disabilities were as competent as the control group in this task. The study would have benefitted from consideration of ethical issues. Vicari et al. (2006) used well standardised measures of visual image inspection (Mental Colour Comparison Test; De Vreese, 1991, and Animal tails; Farah et al., 1988) which examined mental image inspection skills, in a well-designed and well-conducted study. Individuals with Down syndrome performed significantly worse than typically

developing children on mental colour comparison and animal tails tasks. This contrasted with their performance on mental transformation tasks, suggesting participants with Down syndrome may have a specific deficit in image inspection compared to other aspects of mental imagery.

7.1.3.3. Location-Based

In contrast to object-based tasks, several studies compared spatial- or location-based tasks. Roskos-Ewoldsen et al. (2006) used a map scanning task to assess mental imagery inspection. This quasi-experimental study was methodologically sound, and of high quality (although no ethical considerations were reported). They found that participants with intellectual disabilities needed additional trials to learn the landmark locations (although this was not statistically significant) and showed overall slower response times, both of which would be expected due to the nature of intellectual disability. Scanning times increased with scanned distance for all participants as expected. They concluded that no specific deficit in image inspection is seen in people with intellectual disability. Courbois (1996) asked participants to inspect an image at 3 different distances. Their results for both people with and without intellectual disabilities were discrepant with predictions from Kosslyn's model as they found shorter response times for longer distances and suggest there may be issues with the experimental paradigm used. Di Nuovo et al. (2018) included a battery of mental imagery tasks in the 'Mental Imagery Test' (MIT). This test contains both object based and spatial based image inspection tasks. Object based tasks are Visualizing letters; Brooks 'F' Test and Representation of shapes of objects. The spatial based task is Map. Whilst this study seems to provide good evidence that people with intellectual disabilities can complete mental imagery tasks, the findings regarding the relationships

between IQ scores, MIT and the MoCA screening tool for cognitive impairment, are difficult to understand. A number of methodological flaws were identified with this study, as detailed above. As scores for different subtests of the MIT are not reported and unavailable from the author it is not possible to distinguish between performance on object or spatial based tasks.

7.1.4. Transformation

Eleven studies specifically examined mental transformation skills, predominantly through mental rotation tasks, but also through using image imposition and subtraction tasks. Seven were rated as ‘Good’ through quality appraisal (Campione et al., 1985; Carretti et al., 2022; Courbois et al., 2007; Hinnell & Virji-Babul, 2004; Meneghetti et al., 2018; Uecker et al., 1994 and Vicari et al., 2006). Three were rated as Mixed (Borys, 1980; Courbois, 1996 and Doerr et al., 2021). One was rated as poor (Di Nuovo et al., 2018).

Several studies found evidence that people with intellectual disabilities had relatively well-preserved mental transformation skills. Campione et al. (1985) report a high quality, methodologically sound study which found that groups with and without intellectual disabilities were equivalent on tasks at baseline, with both groups being able to learn and master mental rotation, imposition, and subtraction tasks. Both groups required the same amount of input to master tasks, although groups without intellectual disabilities retained and generalised rules better. Carretti et al. (2022) included Ravens Coloured Matrices tasks in their cross-sectional study with a large sample size, in order to provide developmental age equivalent scores for participants with Down Syndrome. No additional information about performance on this task was

provided. Courbois et al. (2007) also reported a high-quality study which compared groups with and without intellectual disabilities and found that adolescents with intellectual disabilities were able to encode and imagine rotations of unfamiliar figures and did not significantly differ in terms of their error rates from chronologically and mental age matched controls (groups of typically developing 16-year-old adolescents or mental aged matched 8-year-old children). Vicari et al. (2006) conducted a robust study comparing participants with Down syndrome who had intellectual disabilities with those who were typically developing and a group of participants with Williams syndrome (who did not have intellectual disabilities). The study used well-standardised measures of visual image transformation (Stick test and spatial rotation test). They reported that individuals with Down syndrome and typically developing children performed at similar levels (i.e., with no statistically significant difference) on the stick test and spatial rotation tasks. Whilst they identified deficits in mental image inspection for participants, they concluded that people with Down syndrome perform similarly to typically developing group on mental transformation tasks.

However, several studies found evidence that people with intellectual disabilities showed an overall impaired performance compared to typically developing participants. Hinnell and Virji-Babul (2004) conducted a robust study and reported that whilst participants with Down syndrome performed mental rotation tasks well above chance level, indicating that the skill set does develop and does exist, it may be compromised compared to typically developing individuals. The study would have benefitted from multiple measures of outcome being taken before and after the intervention. Similarly, Borys (1980) found that participants exhibited a linear increase in their reaction time judgments as a function of increasing angular separation between

stimuli, indicating that participants with intellectual disabilities were using an analogical mental rotation process to perform task. However, they found participants with intellectual disabilities performed slower than the control group and concluded their performance on this task of kinetic imagery is equivalent to that of typically developing children of considerably younger mental ages. This cross-sectional study did not identify confounding factors or consider ethical issues, which could impact the validity of findings. Courbois (1996) found that participants with organic intellectual disability were faster at mental rotation tasks than those with sociocultural cases of intellectual disability. They reported that participants with intellectual disabilities had scores comparable to 5-year-olds, and significantly lower than the 8-year-old comparison group. The categorisation of causes of intellectual disabilities seemed to be made on somewhat arbitrary criterion and is subject to criticism. Uecker et al. (1994) compared performance on a mental rotation task between a control group, a 'learning disabled' group (participants with specific learning difficulties and average IQ) and a Down syndrome group in a well-conducted, robust study (albeit lacking in ethical considerations). The control group were quickest in performing the mental rotation task, followed by the 'learning disabled' group and the Down syndrome group. Participants with Down syndrome were significantly less accurate than the other groups, and the authors concluded that mental rotation skills are arrested in the Down syndrome population. Meneghetti et al. (2018) reported a sound and well conducted study, in which participants with Down syndrome were found to have worse mental rotation performance than typically developing children of comparable mental age, as well as being influenced differently by angular disparity.

Participants displayed specific difficulties regarding the angle of rotation, and the features of stimuli. Doerr et al. (2021) noted that performance decreased with progression of degree of rotation. However, this study failed to identify confounding factors. Both Borys (1980) and Courbois (1996) note that stimuli rotated 180° presented particular difficulty and slower reaction times for participants with intellectual disabilities. Meneghetti et al. (2018) similarly found that participants with Down syndrome were influenced differently by angular disparity, and that for items rotated by 180°, they were unable to perform above chance. Courbois et al. (2007) reported that participants with intellectual disabilities found mental rotation tasks more difficult when stimuli have no feature with a salient axis of elongation. Doerr et al. (2021) examined mental rotation skills in people of different ages with Down syndrome and found that mental rotation performance increased after 5 years of age and continues to improve up to the age of 14 years, after which it decreases.

Di Nuovo et al. (2018) included two tasks that examined mental imagery. These were Cube and Subtraction of parts. Unfortunately, results from these subtests were not presented, although there was no mention of any deficits in performance on these or any subtests of the MIT.

3.2 What Do We Understand About the Phenomenology of Mental Images in People with Intellectual Disabilities Compared to the General Population?

Two papers addressed the phenomenology of mental imagery, both comparing the experiences of people with intellectual disabilities with those of the general population. Brown and Bullitis (2006) considered the ability of people with intellectual

disabilities to generate mental images across different sensory modalities. Whilst 87% of participants with intellectual disabilities spontaneously described visual mental imagery, the authors concluded that a portion of people with intellectual disabilities cannot consistently describe mental imagery.

Regarding the phenomenology of imagery, participants in both groups varied in the vividness of their imagery. Some participants gave transitory accounts of possible imagery while others who gave clear accounts of imagery, described only static pictures, rather than experiencing moving images, similar to a film clip. Several participants declined to image actions such as climbing a stepladder (due to fear of heights) or standing by a fire, suggesting mental imagery can elicit associated emotions in people with intellectual disabilities.

Whilst this study included people with ‘severe to mild’ intellectual disabilities, the number of participants in each category was not given and the relationship between mental imagery ability and level of intellectual disability was not explored. The accessibility of the methodology for people with severe intellectual disabilities is doubtful.

The paper employed a qualitative methodology (interviews and video recordings) to gather data and translated this into quantitative (categorical) data to identify how frequently people with and without intellectual disabilities described mental imagery across different modalities. Whilst direct quotes were used to illustrate aspects of mental imagery, no formal qualitative methodology was employed to analyse the data, and no wider themes reported. Attempts were made to infer mental imagery through the

presence or absence of behaviours such as ‘gross eye movements noted’ or ‘spontaneous laughter at imagery’ which could be attributable to other factors.

In addition to the lack of congruity between the research methodology and the representation and analysis of data, this paper failed to locate the researcher culturally or theoretically and did not consider the impact of the research on the researcher and vice versa. It was given an overall quality appraisal of ‘poor’.

One well-designed, robust study (Brougham et al., 2020) reported aspects of the phenomenology of imagery discovered through their mixed methods study. They found no significant differences were found between groups of people with intellectual disabilities and a comparison group on ability to generate a compassionate image, the type of image generated, and ability to generate compassionate words from their image. Participants with intellectual disabilities required scaffolding to elaborate and build detail of their image (e.g., colour, characteristics). The types of image generated by participants with intellectual disabilities were very similar to those produced by the participants without intellectual disability.

3.3 What Do We Understand About the Role of Mental Imagery Within Existing Psychological Interventions for People with Intellectual Disabilities?

Thirteen studies reported on therapeutic interventions that contained mental imagery as a core component. Eight were rated as ‘Good’ in terms of quality appraisal (Dilly, 2014; Hardiman et al., 2018; Karatzias et al., 2019; Mevissen, Lievegoed, & De Jongh, 2011; Mevissen, Lievegoed, Seubert, & De Jongh, 2011; Mevissen et al., 2012;

Rodenburg et al., 2009 and Stenfert Kroese & Thomas, 2006), three as 'Mixed' (Barrowcliff & Evans, 2015; Buhler, 2014 and Mevissen et al., 2017), and two as 'Poor' (Hart & Robbins, 2014; Rickard et al., 1984).

Eye Movement Desensitisation and Reprocessing Therapy

Nine studies investigated the use of Eye Movement Desensitisation and Reprocessing (EMDR) in people with intellectual disabilities. Generally, EMDR was reported as effective at treating PTSD in people with intellectual disabilities across several good quality studies with a range of designs including a well conducted RCT (Karatzias et al., 2019), ABA design (Buhler, 2014) and a single case study (Rodenburg et al., 2009). A series of studies by Mevissen, Lievegoed, & De Jongh, 2011; Mevissen, Lievegoed, Seubert, & De Jongh, 2011; Mevissen et al., 2017, Mevissen et al., 2012) examined the use of EMDR with children, adolescents, and adults with varying levels of intellectual ability and found it to be effective for people with mild, moderate and severe intellectual disabilities.

Papers made various suggestions and adaptations to EMDR protocol to improve accessibility for people with intellectual disabilities. These included adapting instructions to clients' cognitive and emotional level and using the protocol for children (Mevissen, Lievegoed, & De Jongh, 2011) which allowed participants to be able to put images, thoughts, feelings, and physical sensations into words. Participants with a mental age between 4 and 8 were asked to draw the target image instead of describing it verbally (Mevissen, Lievegoed, Seubert, & De Jongh, 2011). The Story Telling Method (Lovett, 1999) was used with participants of a mental age of 3 years, and typically involved caregivers tell the story of the traumatic event. Occasionally, photos, drawings,

or physical objects are employed to engage the senses and to activate the trauma memory. Clients were accompanied by the trusted person to provide a sense of safety, to overcome communication disabilities, to facilitate an integration of the therapeutic process with daily life and to function as a co-therapist (Mevisen et al., 2012). For those with physical disabilities, carers also supported in holding bilateral stimulation apparatus.

Some studies identified issues in conducting EMDR with people with intellectual disabilities. Barrowcliff and Evans (2015) reported in a single case study where their participant was easily able to generate a safe place through visualisation. However, she required several weeks of imagery practice to support its ready application. Karatzias et al. (2019) conducted a very good quality randomised controlled feasibility trial with qualitative process evaluation and found higher dropout rates for those receiving EMDR plus standard care, compared to those receiving standard care alone. Whilst this could indicate a difficulty with the acceptability of the intervention, this was not reported through qualitative interviews regarding the participants experience of the intervention. However, only 7 of the 15 people receiving EMDR intervention were included in the qualitative analysis.

Imagery appeared to be an important component in managing distress as well as a core component in re-process memories. Dilly (2014) reported a single case study using EMDR with a person with mild ID and complex presentation in a forensic setting. A “safe place visualisation technique” was developed and used in every therapy session to manage participant's arousal. Symptom reduction in re-experiencing, avoidance and arousal were maintained at one- and six-month follow-up.

Imagery Rehearsal Therapy

One study (Stenfert Kroese & Thomas, 2006) examined the use of Imagery Rehearsal therapy for nightmares with two participants with intellectual disabilities. Within this case report, good attention was paid to providing a detailed client history and demographics, as well as a clear description of the intervention. Unfortunately, adverse events and ethical issues were not considered. Clients were assisted to generate new images through discussion with therapist, drawing out new, replacement images to make them more concrete, and practicing the new dream images everyday with help from caregivers. For both participants, nightmares ceased within 6 weeks and progress was maintained at 6 months follow up. The authors conclude that Imagery Rehearsal Therapy is suitable for people with intellectual disability.

Relaxation Training

Hart and Robbins (2014) used three different relaxation techniques (controlled breathing, guided imagery and progressive muscle relaxation). The paper reports a service evaluation, and whilst 23 people were referred to the service, standardised results on an anxiety measure are reported for only six people. In terms of qualitative data, of the 17 people reported to have completed the 12-week intervention, only five provided qualitative feedback. It appears that the three different relaxation techniques were used on an ad-hoc basis with individuals in a 'person centred' program. Due to the study design, it was not possible to directly compare the efficacy of these different approaches. Some participants reportedly preferred guided imagery relaxation strategies, whilst the author acknowledges that ascertaining how well people with limited verbal abilities can engage with guided imagery is problematic. However, results showed a trend towards reduced anxiety after Relaxation Training.

Rickard et al. (1984) compared four groups of participants with differing IQ scores, two of which included participants with IQ scores in the intellectual disability range. Each group consisted of five participants. Each group was presented with a guided imagery relaxation exercise, and of the 10 participants with intellectual disabilities, eight reported being able to engage with the imagery exercise. However, participants with intellectual disabilities did not seem able to use the 10-point Likert scale to self-report levels of relaxation.

Compassion Focused Therapy

Hardiman et al. (2018) report on a compassion focused therapy (CFT) group, which aimed to increase self-compassion, and was evaluated using a mixed-methods design. Exercises to develop this included soothing rhythm breathing and generating a compassionate image of another person or figure, and of generating an image of a safe place. These exercises were practised each weekly session with clients encouraged to practise between sessions. In addition to imagery being a core part of the intervention, it was also used to enhance understanding of verbal material. All participants reported reliable reductions in anxiety but remained above clinical cut-off for diagnosis. Self-compassion improved for all participants, with continued improvement at follow-up for two participants. They concluded that participants may have learned to use mindful breathing and compassionate imagery as effective interventions to help manage short-term distress. Unfortunately, whilst the authors clearly link their research question to their methodology and analysis of data, the effect of the researcher on the research or vice versa was not considered, and no statement was provided locating the researchers in terms of their theoretical or cultural stance. In addition, CFT includes a number of

active components, and therefore any improvements in psychological functioning cannot be attributed to the mental imagery component of CFT.

Discussion

Despite the potential application of mental imagery as a psychological intervention in people with limited cognitive and communication skills, such as people with intellectual disabilities, the literature around mental imagery in this population has not previously been synthesised or appraised.

4.1 Research Question 1: What Do We Understand About the Abilities of People with Intellectual Disabilities to Engage with Mental Imagery (the Generation, Maintenance, Inspection, and Transformation of Mental Images)?

Generation

Generally, there is a body of evidence that people with intellectual disabilities can and do generate mental images in a range of situations and tasks, are as able as the general population to generate images of random patterns and meaningful images. Evidence from five studies suggests that mental imagery consistently improves performance on motor skills tasks in people with intellectual disabilities, possibly because the images required are clearly specified, and concrete, in that they are based on real tasks that participants have already seen or experienced (e.g., Hinnell & Virji-Babul, 2004). Findings that mental imagery improves performance, but not as much as physical practice are in line with findings in the general population. Whilst people with intellectual disabilities can spontaneously use mental imagery as a memory strategy

(e.g., Kwong, 1994), they may require additional prompting and scaffolding to do this, and to generate images that are as clear and distinctive as people without intellectual disability. For those studies examining effects at delayed recall, participants were as good as those without intellectual disability, which is perhaps surprising given the difficulties in memory generally experienced by people with intellectual disabilities. People with intellectual disabilities are successfully able to use mental imagery as a memory strategy. Four of the five studies looking at mental imagery as a strategy to assist memory found that people with intellectual disabilities are successfully able to use this strategy and find it aids recall of material. The one study not finding such results (Gibson et al., 1995) did not provide detailed instructions about mental imagery or check participants were able to do this successfully before the experimental task.

Maintenance

Three papers specifically examined image maintenance. These were rated as good, mixed and poor quality. Therefore, whilst there is some evidence that people with intellectual disabilities can complete imagery maintenance tasks, and that their image refreshing process is relatively efficient, it may be that their abilities are more limited in terms of the complexity of stimuli. In addition, the stimuli used in these tasks are less personally relevant or meaningful when compared to some of the image generation tasks, which again may affect performance negatively. This lack of evidence may be because maintenance is used in other components of mental imagery such as inspection and transformation so not examined specifically.

Inspection

Whilst these studies present some evidence that image inspection skills are comparable to the general population, especially on motor-based tasks, there is a general lack of evidence. There is some evidence that these skills require additional support in terms of time taken to learn tasks and overall slower speed compared to people without intellectual disabilities. It may be that for tasks that are more concrete (such as motor-based tasks), mental image inspection is facilitated.

Transformation

There is mixed evidence regarding the transformation skills of people with intellectual disabilities. Whilst three studies reported participants had no deficit in mental transformation, five studies indicated an overall impairment in this skill. Some aspects of mental rotation may be particularly difficult for people with intellectual disabilities, such as stimuli presented at 180°, or stimuli without a clear axis of elongation. Such stimuli lack personal relevance and meaning and therefore may be more difficult to engage with than other mental images such as a compassionate figure. However there appears to be good evidence that some people with intellectual disabilities can perform mental transformation, albeit at a lower level than the general population.

4.2 Research Question 2: What Do We Understand About the Phenomenology of Mental Images in People with Intellectual Disabilities Compared to the General Population?

Only two studies reported on the phenomenology of mental imagery, and neither of these specifically set out to investigate this, using an appropriate methodology. One

study (Brown & Bullitis, 2006) used a qualitative methodology to explore experiences of mental imagery but did not analyse results using an appropriate method of data analysis, rather converting responses into quantitative categories. Brougham et al. (2020) reported aspects of mental imagery experiences, alongside quantitative findings, and used content analysis to categorise responses. No qualitative method of data analysis was used to analyse open ended questions about experiences of mental imagery.

These studies suggest that people with intellectual disabilities experience mental imagery that is similar in nature to other people but may be less vivid or complex. However, these limitations in reported mental imagery may be due to limitations on verbal communication skills and difficulties in conveying complex and rich mental imagery experiences to researchers. There is some evidence that emotions associated with mental imagery are elicited for this population (both negative emotions such as anxiety associated with an image of a ladder and a fear of heights, and positive emotions such as a feeling of calm when using a compassionate image to self-soothe). Overall, there is a lack of studies exploring the phenomenology of mental imagery in people with intellectual disabilities.

A recent review (Ji et al., 2019) highlights the transdiagnostic role of emotion-laden mental imagery for emotion, motivation and behavioural dysfunction. Whilst the current review identifies some studies into the emotional impact of imagery in people with intellectual disabilities, the impact of emotional mental imagery on motivation and imagery-driven behaviour has not been broached in this population. This is despite the conclusion from Ji et al. (2019) that evidence from the general population suggests that

mental imagery-based cognitions are involved in emotional and motivational processing and have a greater impact on emotional and motivational outcomes (including behaviour) than verbal-linguistic cognitions. This, therefore, remains a notable gap in the literature.

4.3 Research Question 3: What Do We Understand About the Role of Mental Imagery Within Existing Psychological Interventions for People with Intellectual Disabilities?

There is good evidence that EMDR can be adapted to be useful for people with various levels of intellectual disabilities and reduce rates of psychological distress. EMDR uses mental imagery as an essential component (van den Hout & Engelhard, 2012), suggesting mental imagery is accessible to these populations. There was some evidence that people can access other psychological interventions which use mental imagery as a core component, such as Imagery Rehearsal Therapy and Compassion Focused Therapy. However, many of these studies focus solely on treatment outcome and less upon mental imagery and adaptations to promote the use of mental imagery. The literature remains at a preliminary stage, with a reliance on small scale reports and a lack of larger, more methodologically robust studies (with the exception of Karatzias et al., 2019).

Overall, whilst there is some good evidence to suggest that people with intellectual disabilities can engage with all aspects of mental imagery, many studies highlight their need for adaptations such as additional time, support and scaffolding to elaborate and report mental imagery. It appears that mental imagery is not a specific deficit in this population, but due to the nature of intellectual disability, it can be

difficult to tease mental imagery deficits from verbal comprehension difficulties (understanding tasks and instructions) and verbal fluency (reporting the experience of mental imagery). This requires careful consideration to ensure experiments are valid.

How to Facilitate Mental Imagery in People with Intellectual Disabilities

Whilst our theoretical assumption is that people with intellectual disabilities also experience mental imagery, and this is broadly similar to the general population, there are a number of strategies described within the literature to support and enhance the mental imagery of this population. Whilst studies found that people with intellectual disabilities readily use mental imagery in preference to other strategies (Kwong, 1994), other papers reported some difficulties when asking people with intellectual disabilities to engage with mental imagery and described adaptations to facilitate this process.

It was essential to make instructions understandable to participants. Children with intellectual disabilities did not benefit from a simple instruction to generate their own mental imagery (Gibson et al., 1995), which may imply that they are unable to do this without more specific and individualised guidance. People with intellectual disabilities may be less aware of the concept of mental imagery (although this was also the case for several participants without intellectual disability) and may require simplified and more specific, detailed instructions to both understand the concept of mental imagery, and generate mental images (Brown & Bullitis, 2006). One way to ensure participants are engaging in mental imagery during a task is to explicitly ask them to describe this process after the task to ensure mental imagery is employed (Porretta & Surburg, 1995). Adapting instructions to the person's cognitive and emotional level improves accessibility, including the use of materials designed for

children, with appropriate adaptations (Mevissen, Lievegoed, & De Jongh, 2011). Such adaptations may include producing instructions in easy read format and using visual imagery to enhance participants' understanding of verbal material (Hardiman et al., 2018).

Making the imagery task more concrete improves accessibility. This included using physical prompts through which participants could explore and practice a task, before transferring to completing such tasks in their heads (Hinnell & Virji-Babul, 2004). Other strategies included discussing mental images with a client in detail to make them more accessible before drawing out these images on paper with clients (Stenfert Kroese & Thomas, 2006) and talking participants through a practice mental image task to ensure they understand the concept of generating mental images (de la Iglesia et al., 2005). A range of concrete prompts and aids were employed to facilitate mental imagery, including photographs (Brown & Bullitis, 2006), drawings, pictures (Dilly, 2014) and physical objects (Mevissen, Lievegoed, Seubert, & De Jongh, 2011).

In Kosslyn's computational theory of imagery, such maintenance is achieved by the re-activation of visual memory representations in an Object Properties Processing subsystem (Kosslyn, 1980; Kosslyn et al., 2006). One consequence of this shared neural substrate is that mental images can be disrupted by concurrent visual processing (Quinn & McConnell, 2006). Reducing external visual stimulation, through asking participants to shut their eyes, can facilitate mental imagery (Brown & Bullitis, 2006).

Providing extra practice sessions and trials to ensure participants had correctly understood and learned the task was described in several studies (e.g., Hinnell & Virji-Babul, 2004). Participants with intellectual disabilities requires additional trials to learn

the task, reduce the number of errors they made, and demonstrate improved performance (Wilen, 1982). Without such additional time, their results may be inaccurate, with poor performance being due to unfamiliarity with the demands of the task, rather than underlying cognitive deficits (Roskos-Ewoldsen et al., 2006). Additional sessions in which the concept of mental imagery is explicitly explained, and practice exercises completed together, rather than assuming participants with intellectual disabilities already understand this concept can be helpful (Hinnell & Virji-Babul, 2004; Screws & Surburg, 1997). An understanding of how mental imagery is thought to facilitate the task being tested can also be helpful, so that participants have a clear understanding of the experiment and what is being tested (Screws & Surburg, 1997).

Participants benefited from additional scaffolding to help shape and elaborate their responses and provide more correct responses. Strategies included using specific, rather than open ended probes (Jens et al., 1990) or cues, in the form of specific questions (Gordon et al., 1994).

In line with developments in the literature regarding strategies to help people with intellectual disabilities generalise skills outside of the therapy setting (e.g., Crossland et al., 2017), explicitly involved another person may support the process of therapy (Mevissen et al., 2012). During treatment, all clients were accompanied by a trusted person to provide a sense of safety, to facilitate communication, to assist integration of the therapeutic process in daily life and to function as a co-therapist. Mevissen, Lievegoed, Seubert, and De Jongh (2011) adapted a technique used with very young children, whereby parents or caregivers tell the story of the traumatic event, rather than needing the client to do this themselves. Rodenburg et al. (2009) also

suggested that parents or carers could be involved in EMDR treatment where participants are less able to mentalise or verbalise due to their intellectual disability. Stenfert Kroese and Thomas (2006) reported on the importance of a client's mother in helping her adult daughter to rehearse her new dream as part of her nightly routine. They also helped the client to practice generating this image through guiding them through it. The client incorporated generating the image as part of her daily routine.

Many of these adaptations will be familiar to clinicians working with people with intellectual disabilities, as whilst mental imagery requires additional guidance and scaffolding to make it accessible for people with intellectual disabilities, this is also the case for a range of other psychological processes, and is not specific to mental imagery per se. Strategies to help people retain instructions and generalise the use of strategies in different settings are common issues in psychological interventions with people with intellectual disabilities and require the same attention in these settings. Indeed, such adaptations will also be familiar to clinicians using imagery-based interventions with clients without intellectual disabilities experiencing high levels of psychological distress (Holmes et al., 2019).

Limitations of This Review

Within this review, the decision was made to include reports of interventions in which mental imagery is a core component (i.e., mental imagery is explicitly accessed, and such interventions cannot be conducted without the use of mental imagery). These included EMDR and some Compassion Focused Therapy interventions. To exclude such studies, which explicitly rely on mental imagery, would be to miss a substantial body of evidence available to answer the review questions. Similarly, pragmatic decisions were

made to exclude neuropsychological assessments such as Theory of Mind tasks (e.g., the Sally-Anne task) and executive functioning tasks such as Tower of Hanoi. Whilst participants may engage mental imagery in order to complete such tasks, other strategies could also be employed, and without having more information about how participants solved such tasks (which was unavailable in research papers), they could not be unequivocally included as evidence of the use of mental imagery. However, the authors acknowledge that decisions regarding exclusion and inclusion criteria can be critiqued, and that other research teams may have reached different decisions.

Several studies included participants with ‘severe’ levels of intellectual disability (Barrowcliff & Evans, 2015; Brown & Bullitis, 2006; Mevissen et al., 2012). These suggested that people, with severe intellectual disabilities can engage with mental imagery but at a reduced level compared to those with milder intellectual disabilities. No studies included people with profound intellectual disabilities. People with severe and profound intellectual disabilities have an IQ of below 40 and thus marked deficits in their cognitive skills including memory and executive functioning, which are involved in mental imagery (Pearson, 2019). Participants with severe and profound intellectual disabilities face additional barriers to inclusion in such studies including understanding instructions around mental imagery tasks, and difficulties in communicating their experiences of mental imagery to researchers. Studies attempted to evaluate the efficacy of mental imagery interventions through observer reports of non-verbal communication (e.g., body movements during a mental imagery task Brown & Bullitis, 2006, or behavioural indications of distress post psychological intervention Mevissen et al., 2012). However, a lack of robust methodologies mean it is currently impossible to ascertain whether people with severe and profound intellectual disabilities experience

rich mental imagery (and struggle to communicate this imagery to others) or sparse mental imagery.

Implications for Psychological Therapies

This review provides implications for psychological interventions in this population. That mental imagery is experienced by people with intellectual disabilities in a similar (albeit potentially reduced level), suggests that, with appropriate adaptations, mental imagery interventions may be effective for this population.

Within the general population, there are various well-established mental imagery interventions. For example, imagery rescripting reduces distress across a range of psychological disorders, including post-traumatic stress disorder, social anxiety disorder, major depressive disorder and obsessive-compulsive disorder (Morina et al., 2017). This intervention has not been adapted for people with intellectual disabilities, possibly because the understanding of how people with intellectual disabilities use and experience mental imagery has not been established. However, the relationship between an ability to engage with clinical mental imagery interventions and performance on experimental imagery tasks based on Kosslyn's model has not been established in the general population. Indeed, studies regarding the emotional and behavioural impact of imagery may be more relevant for clinical interventions (Ji et al., 2019), and this remains an unexplored area of the literature regarding people with intellectual disabilities.

Additional barriers to providing mental imagery interventions for people with intellectual disabilities include the lack of established evidence base for such interventions. Mental imagery has been extensively investigated within experimental

and clinical psychology, with a number of mental imagery interventions developed to treat psychopathology, including for those with limited cognitive skills including children (e.g. Schwarz et al., 2020). Despite this, such interventions have not yet been considered for people with intellectual disabilities (Hronis, 2021). People with intellectual disabilities are routinely excluded from the development of new interventions due to their additional communication needs and cognitive deficits. However, specific research into interventions for people with intellectual disabilities is hampered by a range of factors including smaller populations which make large scale research difficult to conduct, and a lack of funding available for this marginalised group (Beail, 2016).

A related issue is the lack of standardised outcome measures for people with intellectual disabilities, and there are no validated measures of mental imagery for use with people with intellectual disabilities (see Richardson & Sheikh, 2020 for a review). Without confidence in their ability to measure and work with mental imagery, clinicians working with people with intellectual disabilities may lack confidence to attempt the adaptation of such mental imagery interventions for this population. However, it is of note that idiosyncratic visual analogue scales are frequently used clinically to assess how frequent and distressing mental imagery is for clients within general populations, and to measure change on such dimensions. In the absence of validated scales an individualised approach to assessment and measurement can prove beneficial for treatment development and innovation (Hales et al., 2015).

Implications for Further Research

Intellectual disability is not a unitary condition and encompasses numerous specific disorders and conditions. The literature presented provides evidence for difference in the mental imagery profiles within the intellectual disability population (e.g., Doerr et al., 2021), which requires further investigation.

Research into the phenomenology of an experience (such as mental imagery) would be best addressed using a qualitative methodology with an interpretative analysis, which focuses on lived experiences. An example of this would be Interpretative Phenomenological Analysis, which has successfully been used with people with intellectual disabilities (Rose et al., 2019). One difficulty with asking people to verbally report images is that their compromised verbal skills may impact on the quality and texture of their reports of imagery, thus making it impossible to know whether a report of imagery that lacks richness and texture is due to poor mental imagery skills, or a lack of sufficient verbal skills to describe the experience. Using a range of methods to capture information about imagery (such as asking participants to create drawings of images associated with their mental imagery) may help circumvent this issue and has been used with other clients with verbal communication difficulties (Boden & Larkin, 2020).

The development of standardised measures of imagery, which have been validated for this population will facilitate research in this area and increase the confidence of clinicians exploring mental imagery interventions with people with intellectual disabilities.

The adaptation and evaluation of interventions such as EMDR has been successfully explored and reported through various small-scale research projects. This has allowed for larger, more robust trials of the intervention to be subsequently conducted (Karatzias et al., 2019). In a similar way, effective mental imagery interventions for mainstream populations should be adapted for people with intellectual disabilities. People with intellectual disabilities experience a range of additional communication needs and cognitive deficits. If interventions are successfully adapted to be accessible to this population, they are likely to also be made available to a wider range of people with some additional needs.

Conclusion

Whilst the literature into aspects of mental imagery in people with intellectual disabilities is underdeveloped in comparison to the general population, there exists a range of relatively good quality studies of various designs to support the similarity of mental imagery across both populations. Given the importance mental imagery plays in the maintenance of various psychopathologies, and the effective treatment of various psychological disorders in mainstream services, this review has important implications for the adaptation of such interventions for people with intellectual disabilities.

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Chapter 3

A Systematic Review and Narrative Synthesis of Inclusive Health and Social Care Research with People with Intellectual Disabilities: How are Co-Researchers Involved and What are Their Experiences?

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Abstract

Background: Using inclusive research methods with people with intellectual disabilities

is increasingly common. A recent consensus statement identified key elements when conducting and reporting inclusive research with people with intellectual disabilities.

This review identifies the range of health and social care research topics using inclusive research methodologies, systematically appraises the involvement of researchers with intellectual disabilities and identifies facilitators and barriers to inclusive research.

Researchers' experiences of engaging with inclusive research are synthesised.

Method: Seventeen empirical studies focused upon inclusive health and social care research were identified. The associated inclusive research methodologies employed, and the stages in which researchers with intellectual disabilities were involved, along with the experiences of researchers with and without intellectual disabilities were synthesised.

Results: Papers focused on a broad range of health and social care topics and largely employed qualitative or mixed methods designs. Researchers with intellectual disabilities were frequently involved with data collection, analysis and dissemination. Facilitators of inclusive research comprised sharing power, team working, having sufficient resources and making research methodologies accessible.

Conclusions: Researchers with intellectual disabilities are involved in a wide range of methodologies and research tasks. How the added value of inclusive research is measured and its impact on outcomes, require consideration.

Keywords

Research; Inclusive; Health and social care research; Co-production; Inclusive; Intellectual disability; Systematic review

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Conflict of Interest Statement

The authors declare no conflict of interest.

Data Availability Statement

The data that support the findings of this study are openly available in Warwick Research Archive Portal at <https://wrap.warwick.ac.uk/160232>.

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CRedit Statement

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Introduction

Within health and social care settings, collaborative or participatory research has become increasingly commonplace (Chinn & Pelletier, 2020; Strnadová & Cumming, 2014), with the National Institute for Health Research developing specific guidance around co-production in 2018. A number of terms are used to describe various participatory or inclusive methodologies including 'engagement', 'involvement' and 'inclusion' (Williams et al., 2020). This creates difficulties understanding the amount, level, and type of involvement of those who are not academic researchers.

A broad distinction has been made within the literature between people being passively involved with research as informants or participants, and the active involvement of people within various stages of the production process which includes holding power and making decisions (Abma et al., 2009). Despite this, there remains confusion over the range of terminology and methodologies used within this literature, and the extent to which people with intellectual disabilities are involved in both tasks and processes across the research cycle.

The term 'inclusive research' has been described as any research involving people with intellectual disabilities as "more than just subjects or respondents" (Johnson & Walmsley, 2003, p. 10). As such it encompasses various research approaches traditionally termed 'participatory', 'action' or 'emancipatory'. It includes various forms of involvement by people with intellectual disabilities and refers to collaborations in which people with and without disabilities work together and make equally valued contributions. Inclusive research is driven by values and it aims to

change society through conducting research with people with intellectual disabilities as active partners (Strnadová & Walmsley, 2018).

The increase in inclusive research is due to a convergence of social, political, and cultural change in the active inclusion of people with lived experiences in designing the services they use (Williams et al., 2020). Inclusive research emerged from the struggle for equality embodied in the disabled people's movement (Walmsely et al., 2018) and has been strongly influenced by Social Role Valorisation (Wolfensberger, 1980). The focus on inclusive research has also been driven by the role of funders within some countries more recently, including the United Kingdom (e.g. NIHR), who have expanded their requirements for Public and Patient Involvement (PPI) in research, to promote deeper involvement including co-production methodologies.

As inclusive research has become more widely adopted, researchers have sought to define and identify the added value this methodology provides. Added value has been defined in terms of the contribution inclusive research makes to the quality of the research (both in terms of process and outcomes). In addition, added value can occur at different levels, for example including the effect of being involved in the researcher for the individual, and potentially using the research to affect positive social change (Walmsely et al., 2018). Whilst inclusive research is generally stated to empower researchers with intellectual disabilities and increase the relevance of study results, a range of other outcomes including improving the quality of data and developing services and policies to better meet the healthcare needs of people with intellectual disabilities (Frankena et al., 2019)

Researchers are increasingly aware of the ethical aspects of conducting research with people with intellectual disabilities (Frankena et al., 2019). Conducting inclusive research with people with intellectual disabilities is ethically, methodologically, and practically complex (Bigby et al., 2014). Challenges commonly include the additional resources needed to develop relation-based collaborations and understanding how co-researchers with intellectual disabilities are represented in relation to the wider intellectual disability population (both by themselves and by other research team members) (Chinn & Pelletier, 2020). Other challenges include the nature of support provided to co-researchers with intellectual disabilities, and how transparently this is reported, and considering the nature of knowledge developed from inclusive research (Bigby et al., 2014).

In this review, Johnson and Walmsely's (2003) 'inclusive' research definition was used, which incorporates various active approaches from people with intellectual disabilities providing advice, expertise of lived experiences, and steering a project, through conducting a whole project with support from allies (Bigby et al., 2014). People with intellectual disabilities were not merely participants but part of the wider project and held decision making power. Inclusive research is not conceptualised as recruiting people with intellectual disabilities into research projects, or augmenting research methodologies to promote accrual. Within this definition of inclusive research, various models or ways of conducting the research can be used, with researchers employing several alternative or additional terms within papers, including co-production, participatory action research, and co-design (Bigby et al., 2014). All of these terms fall within Johnson and Walmsely's (2003) definition of 'inclusive' research. However, terms

such as participatory or emancipatory research were not included. The term ‘co-researcher’ has been used to indicate the equal but different contributions of researchers with intellectual disabilities, although the limitations of this term are acknowledged (see Walmsely et al., 2018)

People with intellectual disabilities experience more health inequalities than the general population (van Schrojenstein Lantman-de Valk & Walsh, 2008). Reducing health inequities is a key focus of the NHS long term plan (2019). Despite this, they are a historically marginalised group and routinely excluded from health research (Feldman et al., 2014), especially large-scale research projects and population studies. Whilst people with disabilities have been included in some specific research, this has tended to be as the “objects” of study (Nind, 2013). However, there is growing interest in inclusive health research with people with intellectual disabilities. People with intellectual disabilities also experience higher levels of social deprivation (Emmerson, 2013), which in turn compounds an inability to access preventative healthcare (Pownall et al., 2020). This interaction between social exclusion and health inequalities means both health and social care topics have been included in this review. A broad definition of health research which includes all research that addresses the ‘physical, mental and social health for all populations across the life course (Alliance for Health Policy and Systems Research, 2022, p. iv) has been adopted. Social care topics are defined as those relating to social well-being, social cohesion, the quality of social support, or the capacity to live and manage a social life (Cho et al., 2020).

A recent consensus statement (Frankena et al., 2019) provides researchers with guidelines, agreed upon by experts in the field, regarding attributes of inclusive research

with people with intellectual disabilities. It details ten key elements for reporting and publishing good quality inclusive research with this population. This review uses these two aspects of the consensus statement to understand the extent to which researchers with intellectual disabilities are involved with inclusive research, and to appraise the quality of the inclusive research reviewed. To the authors' knowledge this is the first systematic review using this particular framework.

This review aims to identify the international range of health and social care inclusive research topics, and the various methodologies employed, to systematically appraise the involvement of researchers with intellectual disabilities across different stages and processes of inclusive research, and the facilitators and barriers to inclusive research. The experiences of researchers with and without intellectual disabilities of engaging with inclusive research were synthesised.

Review Questions

1. What are the topics, models and methodologies employed in inclusive research into health and social care topics with researchers with intellectual disabilities?
2. How are people with intellectual disabilities involved in inclusive research in health and social care topics? What are the research tasks and processes they are involved with?
3. What are the experiences of researchers with and without intellectual disabilities of being involved with inclusive research methodologies around health and social care topics?

Methods

The systematic review is reported in line with current PRISMA-S guidelines (Page et al., 2021; Rethlefsen et al., 2021).

Eligibility Criteria

Studies were included if they: (a) reported a completed, empirical research study focused on a health or social care topic, using an inclusive research methodology (i.e. people with intellectual disabilities undertook research alongside academic researchers and held some power and decision making authority), (b) were conducted with adults (18 years or older) with intellectual disabilities and (c) were published after 2000 (following Walmsley's seminal 2001 paper). No exclusion was made on the basis of language, with papers published in all languages considered for inclusion.

Studies were excluded if: (a) participants were not diagnosed with, or self-identified as having an intellectual disability. For papers in which only some co-researchers had an intellectual disability, the paper was excluded unless the results from co-researchers with intellectual disability were presented separately. Papers were also excluded if (b) the paper did not report a completed empirical research study (including papers focusing on facilitating inclusive research methodologies). Only empirical papers were included for several reasons. Papers reporting solely the process or methodology of inclusive research (rather than a specific, inclusive research project) tended to report the generic research process. This review sought to understand the specific details and practicalities of how inclusive research was conducted during a research project, rather than the underlying principles of using inclusive research within a research group or team. This review aimed to understand the areas of health and social care in which inclusive research was being conducted, and without having a

specific research project as the focus of each paper, this was not possible to achieve. However, if an empirical paper met our inclusion criteria and the authors had published a separate paper focusing on the methodology of conducting that research project, we included this paper in our review, in order to answer the research questions more fully. This was the case for two methodologically focused papers (Butler et al., (2012) which reported on the methodology of Tuffrey-Wijne's (2013) empirical paper, and Turk's (2012) methodological paper which reported on the process of conducting Turk's (2010) empirical paper.

Electronic databases (AMED, BNI, CINAHL, EMBASE, MedLine, PsychINFO) were searched through Healthcare Databases Advanced Search and Education Research Complete (through EBSCO), and Web of Science on 11 October 2021 and re-run on 14 March 2022 with no new relevant results identified. No search filters were used.

Grey Literature and Registries

The grey literature was initially searched on 18 November 2021, with searches re-run on 14 March 2022, and no new results identified.

Google scholar (<https://scholar.google.com/>) was searched using the terms (intellectual disability OR learning disability) AND inclusive research. The first 100 results were screened, and no new relevant articles identified.

The British Library EThOS database of dissertations was searched using the terms ('learning disability' OR 'intellectual disability') AND 'inclusive research'. This returned 8 results, none of which met inclusion criteria.

Citation Searching

Backward and forward citation searching was undertaken on 20 December 2021 (forward citation searching was re-run on 15 March 2022), with no additional studies identified. Reference lists of all included articles were manually screened to identify additional studies. Forward citation searching involved checking each included article on Google Scholar and manually screening all articles citing that paper. Articles included in similar reviews and literature searches (Di Lorito et al., 2018; Jones et al., 2020) were checked and one additional study included (Timmons, 2011). For two included studies, a separate paper focusing on the inclusive methodology had been published and was included in this review.

Full Search Strategy

The reproducible searches for all databases are available at <https://wrap.warwick.ac.uk/160232/> and in Appendix 3. Search strategies were comprehensive and included a number of alternative terms and synonyms for inclusive research such as emancipatory research, participatory action research, patient participation, exp* patient participat* and action research. Search terms were peer reviewed by ML and PL, and an experienced librarian. The search is registered with PROSPERO (PROSPERO 2021 CRD42021275031).

Selection Process

7734 results were exported into EndNote, 3899 of which were duplicates that were removed using EndNote's duplicate identification strategy. Results were exported to Rayyan for screening, and an additional 91 duplicate results removed. Rayyan is a free, online tool which can be used to screen and rate papers when conducting systematic reviews. It allows several researchers to complete blind rating of results and

then for raters to compare which results they gave the same or different ratings to, thus providing inter-rater reliability scores.

The initial screening of the 7734 titles and/or abstracts of records was conducted by OH, with a random sample of 20% blindly reviewed by an independent second rater (KT) through Rayyan. There was an inter-rater reliability of 96%, $k = 0.82$, with 15 disagreements discussed and consensus reached on all results through discussion. This included judgements regarding whether the paper focused on a health or social care topic.

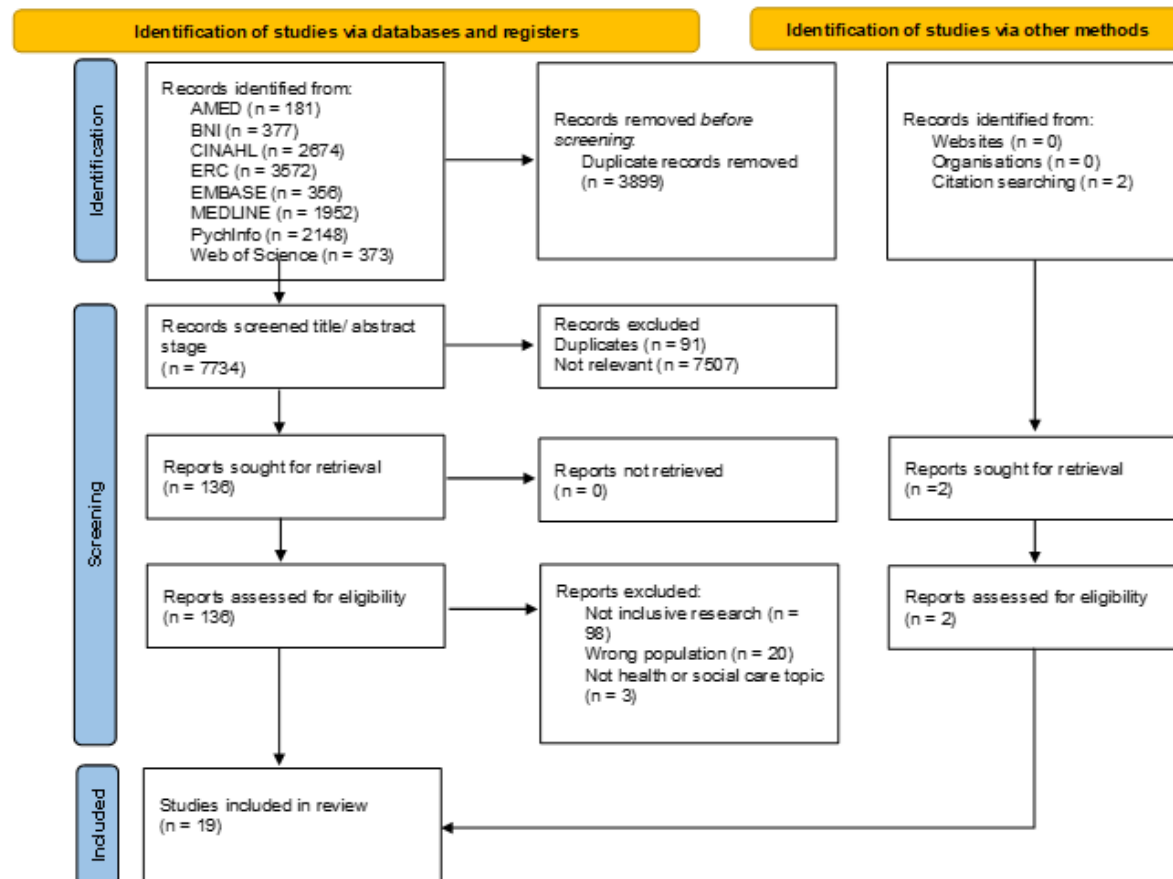
Therefore 136 articles required full text screening, completed using Rayyan. OH read and appraised 100% of texts with the second rated (KT) blindly reading and rating 50% of texts, resulting in an inter-rater agreement level of 94%, $k = 0.84$. Three conflicted decisions were resolved through discussion, and 100% agreement was reached on all studies. Therefore, 19 articles (reporting 17 studies) met the full inclusion criteria (see Figure 1). One paper (Pallisera, 2017) was translated from Spanish by a native Spanish speaker and academic psychologist.

Data Extraction

Data were extracted to include: (a) study reference and year, recruitment source for researchers with intellectual disability and geographical location of study, (b) health or social care topic investigated, (c) study aim, (d) information about researchers with intellectual disability (number, sex, age, population drawn from), (e) model of inclusive research and methodology (f) main findings, (g) stages of research in which researchers

Figure 1

Flow Chart of Study Selection



with intellectual disabilities were involved, and (h) whether the experiences of researchers with intellectual disabilities were included (see Table 2). The data extraction form was piloted by OH and KT on three papers. Data were extracted independently for 100% of articles by OH and 30% of articles by KT. There was an inter-rater reliability of 97%, $k = 0.94$ for data extraction.

Secondly, we developed a further data extraction form based on Frankena et al.'s (2019) 10 key elements for the attributes, potential outcomes, and the reporting and publishing of inclusive health research with people with intellectual disabilities. Frankena's criteria were chosen as the evaluative criteria for this review as they are specifically designed for inclusive health research with people with intellectual disabilities, have been recently published (and therefore are relevant to the literature being reviewed), and were developed using a robust methodology. This allowed for the gathering of information, in a standardised manner about how people with intellectual disabilities were involved in inclusive research, including the various tasks and processes of the research. These 10 elements were broken down into 17 items, and each study was assessed as to whether it met the item (marked 'yes', 'no', or unclear') (see Table 1). Using this framework provided a standardised means of assessing the type and amount of involvement of people with intellectual disabilities both within and across identified studies.

Each study was independently evaluated against these 18 items for 100% of articles by OH and 50% of articles by KT, resulting in an inter-rater agreement level of 94%, $k = 0.87$. All conflicted decisions were resolved through discussion, with 100% agreement reached.

Table 1

The Ten Key Elements for Publishing and Reporting Inclusive Research from Frankena et al. (2019) and the Indicators Used for Identifying How These Were Completed Within Each Paper

Key elements of reporting inclusive research from Frankena et al. (2019)	Indicators used in current review
1 Describe and explain why an inclusive research process was chosen.	1. The paper provides a clear rationale for using an inclusive methodology
2 Describe how decisions were made during the research process, including the level of engagement of team members in these decisions, regarding: recruitment, funding, ethics application, research topic and question, methodology, data collection, data analysis, and data dissemination.	2. A description is provided of how decisions were made in the research process 3. Researchers with intellectual disabilities were engaged in decisions regarding recruitment 4. Researchers with intellectual disabilities were engaged in decisions regarding funding 5. Researchers with intellectual disabilities were engaged in decisions regarding ethics application 6. Researchers with intellectual disabilities were engaged in decisions regarding the research topic 7. Researchers with intellectual disabilities were engaged in decisions regarding methodology 8. Researchers with intellectual disabilities were engaged in decisions regarding data collection 9. Researchers with intellectual disabilities were engaged in decisions regarding data analysis
3 Give all team members' reflection on their experiences with inclusive health research, including barriers, benefits, added value, outcomes, and lessons learned.	10. Reflections were provided within the paper from all team members including researchers with intellectual disabilities
4 Describe how data were disseminated through non-scientific publications, how the voices of all team members were represented in outputs, and how decisions were made regarding authorship.	11. Researchers with intellectual disabilities were engaged with data dissemination
5 Describe how communication and dialogue were facilitated between team members with and without intellectual disabilities.	12. A description was provided of how communication facilitated between team members
6 Describe how support was provided to all team members involved	13. A description was provided of how support provided to all members

7 Describe the research team and each team member's role.	14. A clear description was provided of the research team and the role of all the team members.
8 Describe how health researchers with intellectual disabilities were financially compensated (and, if not, why not).	15. Researchers with intellectual disability were paid, or a clear explanation of why this did not happen was provided.
9 Describe how modifications were made to the research design and process.	16. A clear description of how the research process was modified was provided.
10 Provide an accessible abstract and report to be distributed among people with intellectual disabilities and service providers	17. An accessible abstract was provided within the paper

Data Synthesis

To address research question 1, data was described using the PRISMA statement (Page et al., 2021).

To answer research question 2, a standardised framework specific to inclusive research with people with intellectual disabilities (Frankena et al., 2019) as described above was used to consider the range and type of involvement from people with intellectual disabilities within individual studies, and across the identified literature (see Table 3). Areas where knowledge and evidence were missing were noted, as well as new information and areas of learning.

In addressing research question 3, we employed a deductive approach to thematic synthesis (Thomas & Harden, 2008); see Table 4. Thematic synthesis consists of three stages, that of coding the text, developing descriptive themes and generating analytical themes. All findings, including descriptions and quotes regarding the experiences of researchers (relating to people with intellectual disabilities or other researchers) were coded and then extracted from each paper by OH. Strategies and tools that facilitated and hindered inclusive research were also extracted. Coded data

were clustered to form descriptive themes. These themes synthesised the data and organised data into concepts marked by common characteristics across studies. To generate analytic themes, additional analysis was conducted to infer themes not explicitly identified within papers but inferred from the results presented. Both superordinate and subordinate themes were presented to two team members to discuss and refine syntheses. Issues of trustworthiness of the analysis (in terms of the credibility, transferability, and dependability) were addressed through various tools including the use of a reflexive diary, a detailed audit trail, grounding themes in verbatim quotes, and iterative discussions with the research team regarding representing and displaying data meaningfully.

Results

The 19 papers (reporting 17 studies) were conducted in six countries, with 59% (n=10) in the UK. Other countries included Ireland (n=2), Spain (n=2), the USA (n=2), and Malta (n=1). The number of researchers with intellectual disabilities per study ranged from one to 26.

Researchers with intellectual disabilities were recruited through self-advocacy organisations (n=5), open advertisement (n=4), previous collaborations with academic partners (n=2), independent companies (n=3), and support services (n=1).

Table 2*Data Extraction for Included Studies*

Study number	First author (year), Recruitment source, geographical location	Health/ social care topic	Study Aim	Co-researchers with ID (number; sex; age in years; population of co-researchers)	Model of Inclusive research; Methodology	Main findings	Stages of research where involvement occurred	Does study report views of co-researchers
1	Azzopardi-Lane (2015); self-advocacy group; Malta	Sexuality	Explore issues related to sexuality and self-advocacy for people with ID.	N=7; 4F 3M; early 20s to late 50s; people with intellectual disabilities	Inclusive research methods; semi-structured focus groups	people with ID are aware of their sexuality and how it is perceived by others. They wish to make concrete changes in how their sexuality is discussed and supported by others.	Compiling questions for the focus groups Data analysis Disseminating results	no
2	Brooks (2013); open advertisement; UK	Mental health	To adapt and psychometrically test the CORE-OM outcome measure questionnaire for people with a	N=5; 3F 2M; late 20s and early 50s; people with learning disabilities	Inclusive research; administer questionnaire , make adaptations and test	Developed and tested 17 item questionnaire that was appropriate and accessible for people with	Recruiting participants Administering questionnaire Data analysis	yes

			learning disability.		reliability and validity of new measure	a learning disability to evaluate their experience of receiving psychological interventions		
3	Doherty (2020); self-advocacy group; UK	Promoting physical health	to explore the views and experiences of adults with ID in relation to barriers and facilitators to eating well, living well, and to managing their weight	N=2; NG; NG; People with intellectual disabilities	Co-production; semi-structured focus groups	Themes arose around problems accessing routine caring support; a lack of clear and accessible healthy lifestyle information; unmet training needs for carers and support workers; personal income restrictions; and external barriers such as inaccessible services and the widespread marketing and availability of	Co-produce recruitment materials Facilitate focus groups Disseminate results	no

						less healthy foodstuffs.		
4	Franklin (2021); self-advocacy group; UK	Parenting	To explore the experience of stigma in the lives of parents with a learning disability	N=3; NG; NG; People with learning disabilities	Inclusive research; semi-structured interviews	Thematic analysis generated four key themes; (1) positions of powerlessness, (2) assumptions of incompetence, (3) challenging assumptions and proving competence and (4) claiming power.	Designing the project, data collection, data analysis and dissemination of the research	no
5	Gates (2007); open advertisement; UK	Promoting physical health	To examine the effectiveness of health action plans, and the experience of using them	N=2; 1F 1M; NG; People with learning disabilities	Consumer research; semi-structured interviews	People enjoyed doing their Health Action Plan (HAP). Not everyone was clear about the purpose of the HAP. Most HAP meetings were good quality with people with learning disabilities being listened to and given time to respond	Deciding on research topic Data collection Data analysis Disseminating results	yes

						and ask questions.		
6	Haigh (2013); various services supporting people with learning disabilities; UK	Mental health	To explore what makes people with a learning disability happy and satisfied with their lives ('subjective well-being')	Unclear; NG; NG; People with learning disabilities	Inclusive research; semi structured interviews	Lots of things are important for people with learning disabilities to be happy and satisfied with their lives. We put these things into three themes: 'environmental factors', 'enabling and disabling' and 'personal characteristics'	Deciding research topic, collecting data, data analysis and dissemination	yes
7	Hughes (2020); people active in disability rights activities; USA	Promoting positive relationships	To develop and test the feasibility of an accessible Interpersonal Violence prevention program for people with intellectual disability.	N=6; 4F 2M; NG; People who self-identify as having an intellectual disability	Participatory research; adapting an intervention for people with intellectual disabilities through iterative consultation with co-researchers	Adapted a safety awareness program to meet the needs of people of all genders with intellectual disability. Conducted a feasibility test to assess the practicality of	Ensure the accessibility of the course content and materials Dissemination of results	no

						implementing the program		
8	Martin (2021); NG; Ireland	Promoting physical health	To design an education intervention to equip people with intellectual disabilities with information and knowledge to make informed decisions regarding diet and food choices	N=3; NG; NG; people with intellectual disabilities	Co-design; focus groups and individual interviews including Talking Mats	The development of a teaching module which aligns with inclusion, self-determination and the promotion of healthy behaviours in relation to diet for people with mild or moderate intellectual disability.	Deciding on research topic, adapting educational materials, disseminating results	no
9	Mooney (2019); Building Bridges Training; UK	Social inclusion	To find out more about the barriers that stop people with a learning disability being more involved in the community	N=8; NG; NG; People who self-identify as having a learning disability	Inclusive research; focus groups	Themes that limited community access included transport, fear and anxiety, limits on choice and control, risks and personal safety.	Deciding on research topic, data collection, data analysis and writing up results	yes
10	Pallisera Diaz (2017);	Housing	To understand where people	NG; NG; NG; people with	Inclusive research;	Identified the barriers and	Data collection	yes

	previous collaboration with academic partners; Spain		with ID want to live and who they want to live with.	intellectual disabilities	focus groups, photovoice activity	supports to people with ID living independently . Also identified a number of proposals for improving the independent living situation for people with ID	Data analysis dissemination	
11	Rojas-Pernia (2020); self-advocacy service; Spain	Social inclusion	To investigate the experiences of loneliness and social isolation in people with and without intellectual disabilities.	N=8; NG; 19-26; people with intellectual disabilities	inclusive research; semi-structured interviews	Social relationships are important for young people both with and without learning disabilities. A person may want or need to be alone, but nobody wants to feel lonely	Deciding on research topic, conducting interviews, data analysis, dissemination	yes
12	Salmon (2019); Inclusive Research Network; Ireland	Housing	To explore the experiences of people with intellectual disabilities in	N=26; NG; NG; people with intellectual disabilities	inclusive research, collaboratively designed; structured	Thematic analysis yielded four themes: “expressing	Identify research, plan and conduct	no

			Ireland when moving home using an inclusive research approach		interviews	choice” in the moving process; “feeling connected or isolated when moving”; “accessing supports during and after the move”; and finally, participants’ reflections on “experiencing vulnerability and feeling safe” while resettling.	interviews, data analysis, writing results	
13	Tilley (2012); Building Bridges Training; UK	Social inclusion	To identify the barriers in the lives of people with a learning disability that make life difficult for us and people like us	N=11; NG; NG; People who self-identify as having a learning disability	inclusive research using action research approach; focus groups, interviews	Main findings were around coping day to day and support, poverty, friends and social networks and losing our children	Deciding research topic, being research participants, disseminating results	yes
14	Timmons (2011); open advertisement; USA	Employment	To identify factors that shape the employment-	N=1; NG; NG; people who self-identify as	participatory action research; semi-	Factors influencing employment-related	Ensuring accessibility of research materials,	no

			related decisions of individuals with Intellectual and/or Developmental Disabilities (ID/DD).	someone with ID/DD	structured interviews	decision-making include: The family in the formative years, school-based staff and early employment experiences, the culture of the Community Rehabilitation Providers, the job developer, and personal preferences	co-conducting interviews, data analysis	
15	Tuffrey-Wijne (2013) (empirical paper); Butler (2012) (methodological paper); recruited through previous contact with university researchers; UK	Communicating health information	To explore how to break bad news to people with intellectual disabilities	N=2; 1F 1M; NG; people with intellectual disability	Doing research together; focus groups, interviews	Ten guiding questions developed to help people think about how best to break bad news of a significant diagnosis to someone with ID	Conducted focus groups, data analysis, writing results	yes

16	Turk (2010) (empirical paper); Turk (2012) (methodological paper); open advert; UK	Promoting physical health	To evaluate the implementation of a personal health record for people with ID	N=4; NG; NG; people with intellectual disability	Inclusive design; Randomised Controlled Trial, interviews, checklists	The intervention did not increase attendance at GPs or other health care services.	devising, piloting and administering the research interview, administer research instruments, data coding	yes
17	Watchman (2021); NG; UK	Social inclusion	To identify effectiveness of psychosocial interventions in social care settings for people with ID and dementia	N=5; NG; NG; People with an intellectual disability	inclusive research (participatory action research); mixed methods design; semi-structured interviews, longitudinal and cross-sectional surveys and structured observations	Seventy-four percent of individual goals met or exceeded expectations with reduction in some “as required” medication. Qualitative findings include themes of enabling care and interventions as tools for practice. Photovoice provided insight into previously unreported	Grant application Data collection Data analysis Disseminating findings	no

						fears about dementia		
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Research Question 1: What are the Topics, Models and Methodologies Employed in Inclusive Research With Researchers With Intellectual Disabilities?

Inclusive research addressed a wide range of health and social care topics including promoting physical health (n=4), social inclusion (n= 4), housing (n=2), mental health (n=2), sexuality (n=1), parenting (n=1), promoting positive relationships (n= 1), employment (n=1), and communicating health information (n=1).

Studies used various terms including inclusive research (n= 10), co-production (n=1), participatory or participatory action research (n=2), co-design (n=1), consumer research (n=1), and doing research together (n=1).

Most studies employed a qualitative or mixed methods design. Thirteen studies collected data through interviews (seven structured and six semi-structured), 10 used focus groups, three administered questionnaires, one used direct observation, and one employed a randomised controlled trial design. Studies employed one or more than one method of data collection.

Research Question 2. How are People with Intellectual Disabilities Involved in Inclusive Research? What are the Research Tasks and Processes They are Involved With?

We drew upon Frankena et al.'s (2019) consensus statement for a standardised perspective on the various stages of research in which researchers with intellectual disabilities were included. This encompassed both specific research tasks as well as the processes of research running throughout a project such as working as part of a team. The specific indicators are provided in Table 1.

People with intellectual disabilities were reported to be involved with various stages of inclusive research (see Table 3) such as recruitment (n=10), applications for

funding (n=2), ethical applications (n=5), deciding on a research topic (n=8), making decisions about the methodology (n=13), data collection (n=14), data analysis (n=13), and disseminating findings (n=14), which included providing an accessible abstract or summary (n=13). Studies ranged considerably as to how many different tasks involved researchers with intellectual disabilities. Some studies (e.g. Gates, 2007) involved researchers with intellectual disabilities in nearly every aspect of the research process, whereas others such as Hughes (2020) and Martin (2021) engaged them in discrete aspects of the research.

Frankena et al.'s (2019) statement also considered the process of conducting research. Most studies (n=14) gave a clear rationale for using inclusive research. Seven studies did not state how researchers with intellectual disabilities were included in decision making. Reflections from all team members were provided by 11 papers and facilitating communication between team members was described in 12 papers. Thirteen papers described the role of all team members, and how they were supported to engage in inclusive research. Only six papers either stated that people with intellectual disabilities were paid for their work or explained why payment did not happen. Most papers (n=13) described adaptations to the research methodology to improve accessibility for all researchers. Detailed descriptions of how each of these tasks were specifically conducted were not generally included in these papers, as papers included in this review reported an empirical research project and therefore limitations of space may have prevented this.

Table 3

How Different Studies Met Standards in Inclusive Research

Study number	Author (date)	Rationale for inclusive method	Describe how decisions made	Engaged in recruitment	Engaged in funding	Engaged with ethics application	Engaged with research topic	Engaged with methodology	Engaged with data collection	Engaged with data analysis	Engaged with data dissemination	Reflections from all members	Communication facilitated between team members	Support provided to all members	Describe members role	People with ID paid	Amendments to research process	Accessible abstract
1	Azzopardi-Lane (2015)	unclear	yes	yes	no	no	no	yes	yes	yes	yes	no	no	no	unclear	no	yes	yes
2	Brooks (2013)	yes	unclear	yes	no	no	no	yes	yes	yes	no	yes	yes	yes	unclear	no	yes	yes
3	Doherty (2020)	yes	unclear	yes	no	yes	unclear	yes	yes	yes	yes	no	no	no	yes	yes	yes	yes
4	Franklin (2021);	yes	no	no	no	no	yes	yes	yes	yes	yes	no	yes	yes	yes	no	no	no
5	Gates (2007);	yes	yes	yes	yes	yes	yes	no	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
6	Haigh (2013);	unclear	yes	no	no	no	yes	yes	yes	yes	yes	yes	yes	yes	yes	no	yes	yes
7	Hughes (2020);	yes	yes	no	no	no	no	yes	no	no	no	no	yes	yes	yes	no	yes	no
8	Martin (2021);	yes	yes	no	no	no	yes	yes	no	no	yes	no	no	no	yes	no	no	yes
9	Mooney (2019);	yes	yes	yes	no	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	no	yes	yes
10	Pallisera Diaz (2017);	yes	no	unclear	no	no	no	unclear	yes	yes	yes	yes	yes	unclear	no	no	yes	yes
11	Rojas-Pernia (2020);	yes	yes	yes	no	unclear	yes	yes	yes	yes	yes	yes	yes	yes	yes	no	yes	yes
12	Salmon (2019);	unclear	yes	yes	no	unclear	yes	yes	Yes	yes	yes	no	yes	yes	yes	no	yes	yes
13	Tilley (2020);	yes	no	yes	unclear	unclear	yes	yes	Yes	unclear	yes	yes	yes	yes	yes	yes	yes	yes
14	Timmons (2011);	yes	yes	Yes	no	yes	no	yes	Yes	unclear	no	no	no	yes	yes	yes	no	no

15	Tuffrey-Wijne (2012) (empirical paper); Butler (2012) (methodological paper);	yes	yes	no	no	yes	no	no	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
16	Turk (2010) (empirical paper); Turk (2012) (methodological paper);	yes	yes	no	no	unclear	no	no	no	yes	Yes	yes	yes	yes	yes	yes	yes	no
17	Watchman (2021);	yes	yes	unclear	yes	unclear	unclear	yes	yes	yes	yes	no	no	no	no	no	no	yes
	Total number of studies meeting this criterion	14	12	9	2	5	8	13	14	13	14	11	12	12	13	6	13	13

Research question 3: What are the Experiences of Researchers With and Without Intellectual Disabilities of Being Involved With Inclusive Research Methodologies?

A deductive approach to thematically synthesising the papers was used (Thomas & Harden, 2008), resulting in seven superordinate themes being identified (see Table 4).

Experiences of both researchers with intellectual disabilities and other research team members regarding conducting inclusive research were reported. Facilitators and barriers to the methodology were identified. Themes related to the ethical justification for inclusive research, the additional resources required to undertake inclusive research, practical aspects of making such research accessible, and wider, indirect effects of undertaking inclusive research.

Theme 1: Negotiating Who's Responsible for the Research and How We Share Power

Understanding Who Directs and Holds Power in the Research

Projects that involved researchers with intellectual disabilities in decision-making from the design stage (e.g. Mooney, 2019) enabled them to hold power. Responding to the input from researchers with intellectual disabilities encouraged them to lead in decision making. Researchers with intellectual disabilities needed to be empowered to negotiate with and challenge colleagues, which was facilitated through involving self-advocacy organisations.

Table 4*Thematic Synthesis of Studies*

Superordinate Theme	Subordinate themes	Example of supportive quote and reference	Number of studies endorsing theme
1. Negotiating who's responsible for the research and how we share power	Understanding who directs and holds power in the research	<i>"It is important to have someone who knows about research to keep things on track, but it is also important to remember the research belongs to everyone."</i> (Haig, 2013)	13
	The ethical argument for people with intellectual disabilities holding control and power in the research	<i>"We are proud of our reports – and we are proud that we got awarded a lottery grant! This made us feel what we had to say was important."</i> (Tilley, 2012)	11
	Agreeing that research is jointly owned	<i>"We have enjoyed doing the research together"</i> (Butler, 2012)	14
2. Conducting research is a meaningful experience, even when it's boring	Engaging in research is enjoyable	<i>"It was very exciting to be part of such an innovative research process."</i> (Turk, 2012)	14
	Aspects of research can be challenging	<i>"Research can be boring and hard work sometimes"</i> (Haig, 2013)	16
	Acknowledging the added value of inclusive research	<i>"The study entailed collaboration between the lead researcher and adults with intellectual disabilities to generate new knowledge that neither could produce alone"</i> (Doherty, 2020)	16

3. It helps to be able to work as a team	Good collaborative working is essential	<i>"We really enjoyed working as part of a team and we think it is really important for people with and without a learning disability to work together in research."</i> (Haig, 2013)	16
	Being clear about everyone's roles is helpful	<i>"The combination of expertise and respectful partnership between people with intellectual disability, service providers and academia resulted in an educational initiative that met student's needs."</i> (Martin, 2021)	16
	Understanding how we work with the wider project team	<i>"For example, instead of having to completely rewrite an evaluation question that [we] had agreed upon, a NAB member [with intellectual disability] offered a slight change in wording"</i> (Hughes, 2020)	13
	Everyone is equal	<i>"We think it is important to remember that people have different skills but equal value."</i> (Haig, 2013)	13
4. Inclusive research requires additional resources	Developing and practicing new research skills	<i>"As academic researchers we have acquired new skills related to listening to collaborators with disabilities, to the organization and presentation of the information in an accessible way and to the continuous adaptation of research activities to a dynamic that favors the active and collaborative participation of everyone involved"</i> (Pallisera, 2017) <i>"Our researchers with learning disabilities have been trained 'on the job'. We are learning by trial and error. This has worked alright so far, but it would be wonderful to be able to offer formal research training and a qualification to people with learning disabilities interested in becoming researchers."</i> (Butler, 2012)	17
	Additional practical support is essential	<i>"All researchers were employed for short research days to facilitate access to off peak transport, help researchers with ID and carer researchers overcome the problem of salaries resulting in benefits being lost, and reduce tiredness and overload."</i> (Turk, 2012)	16
	Additional emotional support is needed	<i>"Before we started, we thought about what might happen if people told us about things that were sad or difficult to hear, but it is not always easy to prepare for how you are going to feel when this happens."</i> (Haig, 2013)	14

	Inclusive research requires time	<i>“Getting groups together was much more difficult than we thought...One of them took a whole year to negotiate and set up” (Butler, 2012)</i>	16
	Inclusive research requires additional finances	<i>“The funding provided inbuilt flexibility to facilitate the creative solutions sometimes needed to overcome hurdles that occurred during the research period” (Turk, 2012)</i>	16
5. How can inclusive research be made accessible?	We need to use multiple strategies to improve the accessibility of the research process for everyone	<i>“The main challenge that had to be addressed in a design including adults with ID as researchers, was to ensure all elements were ethical and non-exploitative, e.g. the potential researchers had to be able to understand the research, and the tasks had to be reasonable and realistic for someone with ID to complete. (Turk, 2012)</i>	17
	There must be flexibility in our research methodologies to improve accessibility	<i>“Flexible. Each group had different needs and wishes. One group wanted Irene to explain facts about cancer, so she prepared a slide show for this. One group wanted more pictures and stories to think about. One group wanted more time to talk about their experiences. We also included some role-play” (Butler, 2012)</i>	16
6. Where does inclusive research fit into wider project timeframes?	Thinking about endings from the beginning	<i>“Help was built in from the beginning to prepare the researchers for the eventual end of the project, e.g., personal development plans, writing curriculum vitae” (Turk, 2012)</i>	9
	Inclusive research should be built in from the beginning of the project	<i>“We developed a research project with the group and asked our local NHS research network for money for this. They agreed but first we had to get ethical approval from the local ethics committee (LREC). This took quite a while to do, as we had to fill in a long form, much of which was not relevant to this kind of research” (Gates, 2007)</i>	8
	The need for longer term collaborations	<i>“Policy shift is required to provide resources on an ongoing basis to support meaningful longer-term engagement with wider reach.” (Watchman, 2020)</i>	9

7. Through involvement in inclusive research, people experience additional benefits.	We made new relationships	<i>“Opportunities to connect with peers in a supportive environment, can contribute to the ongoing social development and inclusion of people with intellectual disability” (Hughes, 2020)</i>	12
	We feel more confident	<i>“[Researchers with intellectual disabilities] found participation in the research useful for them to learn more about society, to have greater confidence in a group setting, to learn important things about the future and to improve their self-esteem as their opinions are valued...We (as academics) have learned to design and implement accessible information, facilitating strategies that we can extrapolate to teaching and other research activities.” (Pallisera, 2017)</i>	11
	Becoming agents of change	<i>“Some members raised concerns impacting the intellectual disability community, ranging from perceptions about their intellectual capacities, and discriminatory language, gestures, and other behaviors.” (Hughes, 2020)</i> <i>“[The research] allowed the project to progress its broader aims to reduce societal stigma and increase progressive attitudes towards the parenting rights of people with learning disabilities” (Franklin, 2021)</i>	14

The Ethical Argument for People With Intellectual Disabilities Holding Control and Power in the Research

Most papers identified that people with intellectual disabilities should hold more power because of *“how important it is to have people with learning disabilities involved in studies right from the start, because it means that the studies really matter to them”* (Researcher without intellectual disability; Butler, 2012). Such research can directly impact their lives in a way that was different from academics.

Agreeing That Research is Jointly Owned

Stakeholders viewed the research as a joint endeavour, with *“the active and collaborative participation of everyone involved”* (Researcher without intellectual disability; Pallisera, 2017). Most papers endorsed joint ownership and saw this as a separate from research expertise: *“We think it is important for people to research together. We believe that everybody has different skills that they bring to research whether or not they have a learning disability. These skills are different, but all are important.”* (Haig, 2013).

At times researchers without intellectual disabilities struggled not to take over the research and understand how much guidance and support they should be providing. Awareness of the power imbalance between researchers with and without intellectual disabilities was important.

Theme 2: Conducting Research is a Meaningful Experience, Even When it's Boring Engaging in Research is Enjoyable

Most studies described inclusive research as enjoyable and meaningful. Those with intellectual disabilities liked their role in disseminating results: *“People were really interested in our ideas. It showed on their faces how interested they were... I felt valued for what I did... Its' good to tell people what I've been part of and what I've been doing*

(because) we are doing a good job and it's important to help people. (Researcher with intellectual disability; Brooks, 2013). Academic partners found it *“very exciting to be part of such an innovative research process”* (Researcher without intellectual disability; Turk, 2012).

Aspects of Research can be Challenging

The difficulties with inclusive research were acknowledged in nearly every study, with researchers stating: *“All found some parts of the research process hard”* (Researcher without intellectual disability; Turk, 2012). Including researchers with intellectual disabilities was difficult regarding applying for funding (only two papers described this), ethical approval (six studies) and paying researchers (eight studies). Having lots of researchers with intellectual disabilities led to issues with consistency around data collection (Salmon, 2019).

Acknowledging the Added Value of Inclusive Research

Researchers with intellectual disability and other stakeholders both described the additional benefit of using inclusive methodologies in all studies. The lived experiences of people with intellectual disabilities was perceived to improve research: *“We can contribute many things from our own experience ... If they are talking about disability, what better teachers than ourselves?”* (Researcher with intellectual disability; Pallisera, 2017). Academics described inclusive research as *“generat[ing] new knowledge that neither could produce alone”* (Researcher with intellectual disability; Doherty, 2020). However, as only 12 studies included direct reflections from all team members, the voice of researchers with intellectual disabilities was not always present.

Theme 3: *It Helps to be Able to Work as a Team*

Good Collaborative Working is Essential

Developing and maintaining collaborative relationships was key for researchers with intellectual disabilities “*The most important thing is to build good relationships with the people you are researching with*” (Haig, 2013) and for stakeholders without intellectual disabilities in almost every study. Build trusting, respectful relationships, required time together both informally (e.g. shared lunches) and in research meetings, and a team ethos that included humour and camaraderie. Enthusiasm from all team members around using an inclusive methodology was essential. Participants reported that setting ground rules facilitated open and honest discussions, with 14 studies addressing communication between all team members. Some researchers felt that building on existing working relationships with researchers with intellectual disabilities facilitated this process, as team members already knew each other well.

Barriers to team working included interpersonal difficulties between team members, and a need for awareness and reflection around interpersonal dynamics.

Being Clear About Everyone’s Roles is Helpful

The importance of clearly defined roles within the research team was stated in nearly every study, for researchers with intellectual disabilities “*[We] have collectively built a new role as researchers*” (Pallisera, 2017), academics without intellectual disabilities “*There is a need for clarity and a division of roles*” (Brooks, 2013), and participants with intellectual disabilities “*Everyone had their specific role in the focus groups, and that was really good. It was clear to each of us what we were there for, and I think it was clear to the participants as well. That really helped.*” (Butler, 2012).

Understanding How We Work With the Wider Project Team

Having a wider project advisory or reference group which also contained people with intellectual disabilities could be helpful. It provided overview or steering in case of disagreements or uncertainty and was especially useful for larger projects recruiting across multiple sites. For example, Hughes et al. (2020) worked with six researchers with intellectual disabilities at a local level, and in addition convened a National Advisory Board (NAB). The NAB included three researchers with intellectual disability and was responsible for overall guidance and monitoring of the project.

Everyone is Equal

The idea that all researchers should be seen as equally valued team members was strongly endorsed by both researchers with intellectual disabilities and stakeholders without intellectual disabilities in three quarters of studies. Whilst genuine collaboration can improve the quality of academic research, disagreements needed to be discussed with everyone having an equal voice “*there were times when we [academics without intellectual disabilities] struggled not to take over*” (Brooks, 2013). Recognising researchers with intellectual disabilities as colleagues of equal value involved “*listening, knowing, negotiating, arguing, addressing and finding new ways to be together*” (Researcher without intellectual disability; Rojas Pernia, 2020). Academic researchers sharing their vulnerabilities and listening to and being willing to learn from colleagues with intellectual disabilities was important.

Theme 4: Inclusive Research Requires Additional Resources

The additional resources required for inclusive research was acknowledged by all research teams.

Developing and Practicing New Research Skills

The resources needed for people with intellectual disabilities to develop their research skills was identified as an issue by almost all papers. These included appropriate research training, and support to practice skills with colleagues. Eight papers described providing training in the specific research skills and methodologies required for the research project being undertaken, whilst five discussed providing more generic research skills to co-researchers with intellectual disabilities. Engagement with research training was enhanced through practical tasks, workshops and exercises. Working together on research tasks helped all researchers develop skills. Researchers with intellectual disabilities focused on practical aspects of research: *“We also learned some practical things about research. Some of us felt nervous before we interviewed people, so it was helpful to have some water to drink.”* (Haig, 2013). Academic partners developed new skills: *“We (as academics without intellectual disabilities) have learned to design and implement accessible information, facilitating strategies that we can extrapolate to teaching and other research activities”* (Pallisera, 2017).

Additional Practical Support is Essential

Researchers with intellectual disabilities required additional support: *“The consumer researchers need support from the main researcher and steering group with liaising with key workers and support staff at home and at the day centre, travel training, accompanying the consumer researchers to various locations, sorting out travel arrangements, help with the management of their diaries and support with benefit issues”* (Researcher without intellectual disability; Gates, 2007). Teams used support workers, personal assistants, research and writing mentors to support researchers with intellectual disabilities with various tasks, including travelling to research meetings and collecting data. Working flexible hours helped reduce fatigue for all researchers. Several

papers mentioned that payments could impact on researcher's benefits and negotiating contracts with universities could be complex.

Additional Emotional Support is Needed

Three quarters of teams considered managing the emotional toll of conducting research into difficult topics, through talking about difficult feelings, agreeing ground rules and getting additional support (e.g. Mooney, 2019). Protecting researchers with intellectual disabilities by excluding them from emotionally sensitive topics was discouraged: *"No subject is too difficult for people with learning disabilities to think and talk about"* (Butler, 2012). Instead, acknowledging difficult feelings and accepting the complexity of research was valued.

Even with careful consideration of extra support, challenges arose: *"There is...an understanding that this process requires a lot of time, a lot of commitment and a lot of care. And even with all of this, inclusiveness can slip!"* (Brooks, 2013).

Inclusive Research Requires Time

This subtheme was acknowledged almost universally by academic partners concerned about how long processes took: *"It would have been cheaper and easier to employ paid professional researchers to carry out the research."* (Researcher without intellectual disability; Turk, 2012). Additional time was needed across projects, as well as during specific stages (e.g. training, data analysis). Time spent initially forming cohesive teams was well invested, as was ensuring researchers with intellectual disabilities understood the research.

Stakeholders acknowledged the additional benefits of inclusive methodologies *"All those involved believe the benefits outweighed the costs in terms of the richness of*

the experience and the outcomes obtained” (Researcher without intellectual disability; Turk, 2012).

Inclusive Research Requires Additional Finances

Almost all studies noted that additional finances are required: *“This costs money! You need to have enough money in your budget to pay for extra time and for support workers to assist the researchers if necessary”* (Butler, 2012).

Accessing appropriate funding for inclusive research could be challenging, both in terms of having input from researchers with intellectual disabilities at the beginning of a project (before funding is secured) and accessing funding for specific tasks (e.g. writing papers and disseminating results).

Theme 5: *How Can Inclusive Research be Made Accessible?*

We Need to Use Multiple Strategies to Improve the Accessibility of the Research Process for Everyone

This was identified as an important theme by all researchers, both in making the methodology accessible for team members and presenting findings appropriately: *“Sometimes it is hard to write research in a way that makes sense and is useful to everybody.”* (Haig, 2013). Stakeholders described how, working closely with researchers with intellectual disabilities, they: *“Acquired new skills around the organization and presentation of the information in an accessible way”* (Researcher without intellectual disability; Pallisera, 2017). Fifteen papers provided an accessible abstract.

Presenting data in multiple formats (e.g. combining picture cards, with information being read out and simultaneously presented in large type) was helpful. Using diagrams, photographs and sticky notes allowed data to be manipulated more easily. Shifting from predominantly verbal discussions to activity-based exercises was

helpful. The pace of meetings needed to be suitable for everyone, although working at a slower pace could be frustrating. Meetings could require additional preparation to ensure accessibility. Using existing meetings and groups ensured accessibility of locations. Having academic researchers experienced in working with people with intellectual disabilities was helpful. Obtaining meaningful feedback from researchers with intellectual disabilities required skilled colleagues. Several teams wanted to present their research using plain English, but found this hard, especially in academic papers. Ensuring all aspects of the project were conducted to the highest ethical standards, meant that researchers with intellectual disabilities understood all tasks and such tasks were reasonable. Four papers would have liked to include people with moderate or severe intellectual disabilities but were unsure how to do this. Two papers identified that researchers with intellectual disabilities felt uncomfortable asking intimate questions of participants.

[There Must Be Flexibility in Our Research Methodologies to Improve Accessibility](#)

Most studies engaged researchers with intellectual disabilities in the methodology, and 13 described amendments to the project. Allowing individuals to focus on their skills, rather than expecting all researchers to undertake all tasks, was helpful for some teams, whilst others initially planned for team member to undertake specific roles but later found collaborative working a more effective strategy. Some studies found data collection strategies were less successful than anticipated and needed amending. Being adaptable was seen as key inclusive research, as endorsed by almost all studies. It generated new thinking and ideas and made the research accessible to all.

Theme 6: *Where Does Inclusive Research Fit into Wider Project Timeframes?*

Thinking About Endings from the Beginning

Over half of studies planned for the ending of the project when commencing the research, which managed the team's expectations. Visually representing tasks and progress helped the team to prioritise. Researchers with intellectual disabilities were meaningfully involved disseminating results through training, conference presentations, making films and writing papers. Thinking about how researchers may wish to continue and develop their research skills, and other transferable skills were included in this theme.

Inclusive Research Should be Built in From the Beginning of the Project

Early involvement by researchers with intellectual disabilities ensured they found projects meaningful, important, and interesting, and was considered in half of papers. However, obtaining funding often required a developed project plan, leaving researchers with intellectual disabilities unpaid during early stages of the research. This inability to pay researchers with intellectual disabilities during the planning stages of the project could be seen as unethical. Similarly, ethical approval requires significant work and planning which could hinder the involvement of researchers with intellectual disabilities in the early stages.

The Need for Longer Term Collaborations

The need for more, longer-term inclusive research was noted by over half of studies.

“We think we need to do more research with other people with a learning disability to see whether they agree with the barriers that we have identified” (Mooney, 2019).

Researchers with and without intellectual disabilities working together over several projects develop closer working relationships. The difficulty in a project team critiquing

their own work was noted and was circumvented by liaising with other inclusive research teams.

Theme 7: Through Involvement in Inclusive Research, People Experience Additional Benefits.

We Made New Relationships

This was endorsed by three quarters of papers. Researchers with intellectual disabilities found developing and rediscovering relationships valuable *“It has been good to get to know some people again that we knew from the past ...we have been able to get ‘peer support’ from each other”* (Tilley, 2012). Academics and other stakeholders valued new relationships both personally and professionally *“We have made new friends and significantly enriched the reality of the people with whom we work and research”* (Researcher without intellectual disability; Pallisera, 2017).

We Feel More Confident

Fourteen papers endorsed this theme. Whilst some stakeholders felt more confident presenting information in accessible formats, this theme was widely endorsed by researchers with intellectual disabilities: *“It has made us more confident and able to stand up for ourselves more. Now, we know we do not have to put up with things as they are, but we can challenge them”* (Tilley, 2012).

Becoming Agents of Change

This was identified in 16 papers, as *“self-advocates sought to use this research to bring about concrete change in their lives”* (Researcher without intellectual disability; Azzopardi-Lane, 2014). Stakeholders and academic partners became more active in promoting the rights of colleagues with intellectual disabilities *“one of the CAB members set up a web-based site to help secure funding to attend and co-present with*

the researchers at a national disability conference” (Researcher without intellectual disability; Hughes, 2020), whilst researchers with intellectual disabilities described various activities including holding a *“meeting with the MP for our area”* (Tilley, 2012), collaborating with other academic institutions and disseminating research in accessible and meaningful ways: *“We wanted the research to be accessible to as many people as possible and so we decided to make a film as well”* (Haig, 2013). Inclusive research “allowed the project to progress its broader aims to reduce societal stigma” (Researcher without intellectual disability; Franklin, 2021), engendering change at a different level.

Discussion

This review had three aims: to understand the range of health and social care topics being researched using inclusive research methodologies internationally, and the methodologies employed to do this; to describe how researchers with intellectual disabilities are involved in inclusive research; and to synthesis the experiences of researchers with and without intellectual disabilities.

The topics being researched using inclusive research within health and social care were disparate and included addressing physical and mental health issues, and understanding social issues including social exclusion, employment and housing. This demonstrates the breadth of areas across which inclusive research can usefully be employed, specifically in relation to areas of health and social care in which people with intellectual disability continue to experience high levels of inequality.

Studies employed various methodologies, with qualitative methodologies dominating. Also included were some quantitative, larger scale and multi-site studies,

which provide helpful examples of how such research projects can employ inclusive methodologies.

Inclusive research is being increasingly conducted and reported, both in the UK and internationally. Of the seventeen papers included in this review, eight have been published within the last five years. Inclusive research methods are being championed by funding bodies (e.g. NIHR), and more widely used and taught, meaning this approach has the potential to increasingly influence and improve various research methodologies within the intellectual disability field over the coming years.

The ways in which researchers with intellectual disabilities were involved in studies varied, with some studies involving researchers with intellectual disabilities throughout the research process and others focusing on discrete tasks. This review focused on understanding to what extent researchers with intellectual disabilities were involved in the different tasks as well as the process of inclusive research.

Understanding the quality of inclusive research is complex, as this is intrinsically tied to the nature of the research study itself and therefore cannot be measured simply by the number of research tasks and processes involving researchers with intellectual disabilities. Our use of a consensus statement (Frankena et al., 2019) allowed for these areas to be systematically compared between and across studies, and therefore the extent to which each study met the key elements of inclusive research could be rated. However, the lack of detailed information provided in papers as to exactly how each key element was met (for example specifying in which phases of the research people with intellectual disabilities made decisions, describing exactly how communication was facilitated between team members etc) meant that it was not possible to provide a

detailed overall image of the predominant methods and strategies involved in inclusive research.

Recruiting co-researchers from diverse backgrounds using open advertisement occurred for only four studies in this review. Academic researchers reported that working with existing collaborators with intellectual disabilities facilitated the process because good working relationships had been established. Involving self-advocacy groups was suggested as a means of empowering researchers with intellectual disabilities to challenge academic partners. However, such approaches risk involvement being confined to a subsection of researchers with intellectual disabilities, who no longer hold the position of ‘outsider’. Whether this is an issue depends on whether researchers with intellectual disabilities are seen as representing the experiences of people with intellectual disabilities broadly or contributing their own individual skills (Chinn & Pelletier, 2020).

In line with this study, the range of terms falling under ‘inclusive research’ were highlighted by Jones et al. (2020) although with the publication of Frankena et al.’s (2019) standards this may become less heterogenous in future. Jones et al. (2020) helpfully consider to what extent studies comply with their aims of inclusive research, and found intentions were largely congruent with processes described in the articles.

Contrasting this review with Di Lorito et al. (2018) allowed for recent trends in inclusive research to be identified. Both reviews reported wide variability in the extent of involvement from researchers with intellectual disabilities. They both found that the additional costs of an inclusive research methodology acted as a barrier to the methodology. Both reviews identified appropriate research training, clarity of research

roles, and the need for flexibility and planning to make methodologies accessible. The multiple benefits for researchers with intellectual disabilities, academic partners and research participants were highlighted by both reviews. However, whilst Di Lorito et al. (2018) found that data analysis was an area in which researchers with intellectual disabilities were less likely to be involved, this was clearly described in 13 of the studies in this review, including quantitative studies. Di Lorito et al. (2018) identified long-term impact and change as being missing from studies, while this review found meaningful change being reported both in terms of the impact of accessible dissemination of results, and personal change in 13 studies

Most papers provided insights into how researchers with and without intellectual disabilities experienced conducting the research. However, the way in which some papers were written meant it was not possible to understand whether the experiences reported were those of researchers with intellectual disabilities or of the overall project team. Difficulties in hearing the voices of co-researchers with intellectual disabilities have been highlighted previously (Strnadová & Walmsley, 2018). Guidelines for the reporting of, amongst other items, the distinct experiences and reflections of researchers with intellectual disabilities did not appear to have been used effectively by the papers in this review.

The complexity of conducting research was illustrated frequently in themes in which differing aspects of lived experiences arose, such as in Theme 2 whereby inclusive research was described as both enjoyable (by 14 studies) and challenging (16 studies). Experiences were not universally challenging or enjoyable, but rather experienced as both of these at different times or indeed simultaneously. Honest

appraisals of the experiences of conducting research are important, allowing inclusive researchers to make informed decisions about joining research teams.

The time required to undertake good quality inclusive research was raised by 16 papers. There can be a tendency for academic researchers to see inclusive research as requiring 'additional' time to more traditional research methodologies. However, it may be more helpful to consider that inclusive research takes time, and that sufficient time must be devoted to it, rather than seeing this as a burden when compared to how long other research methodologies may take.

A strong theme of the ethical argument for people with intellectual disabilities controlling research was found in the current review. Di Lorito et al. (2018) found a change in culture was needed to ensure researchers with intellectual disabilities were involved in an ethical manner. The increased use of inclusive methodologies means ethics boards are becoming better able to understand the need for involvement from beginning of projects. Ethical practice dictates that people with intellectual disabilities should be involved throughout research, although ensuring ethical integrity requires careful consideration (McDonald & Kidney, 2012).

Limitations of Review

Inclusive methodologies have been used in studies regarding service development and implementation, and in co-producing interventions, and may be examples of good practice within services. However, the focus of this review was on empirical, inclusive research studies which are less common, and did not include methodological papers describing inclusive research. The tension between producing sufficiently detailed descriptions of the inclusive research methodology and the

limitations of space when reporting an empirical study led to two studies having been described in two separate papers (one empirical and one methodological) as to exclude either would reduce our ability to answer the research questions.

In line with previous reviews (e.g. Di Lorito et al., 2018; Jones et al., 2020) studies in this review focused on people with borderline to mild intellectual disabilities. Those with severe or profound intellectual disabilities were not included as co-researchers, although they were involved as research participants (e.g. Watchman, 2020), and their families and professionals were also included to keep their voice in mind (e.g. Tuffrey-Wijne, 2013). How people with profound and severe intellectual disabilities can be involved in research *for*, rather than *with*, them (Nind, 2013), and how this relates to inclusive research needs revisiting.

Di Lorito et al. (2018) identified a source of reporting bias, in that the direct experiences of researchers with intellectual disabilities were not reported separately from the wider researcher team, meaning the reader cannot be sure that the views contained within the paper represented the specific experiences of such researchers. This was also found in the current review, with 11 papers failing to report such experiences separately. Frankena et al.'s (2019) statement that reflections from all team members should be included in the write up of the study will hopefully improve this.

Future directions

Whilst conducting inclusive research is important, it is equally important to reflect on and evaluate this work to allow greater impact of future inclusive research (Chinn & Pelletier, 2020).

Understanding exactly what has happened in inclusive research projects is essential, both in terms of the scope of inclusive researchers, and evaluating the quality of the research.

The need for appropriate research training for co-researchers with intellectual disabilities was highlighted by a number of authors, despite it not being a specific focus of this review. Having a standardised programme available (e.g. Tuffrey-Wijne, 2020) would reduce the burden of having to develop and deliver this through individual research teams. However, this idea requires careful consideration, due to both the variable experiences and abilities of researchers with intellectual disabilities, and the differing roles undertaken by these researchers. The appropriateness of a standardised training programme has been considered elsewhere (e.g. Walmsley et al., 2018).

That inclusive research is challenging is undisputed, but that it adds value to both the quality of research and for individuals involved in the process is also understood (Walmsely et al., 2018). The challenge is for authors to consistently capture both the impact of this added value within the literature, and the difference it makes to the lives of people with intellectual disabilities (Strnadová & Cumming, 2014).

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Chapter 4

The Phenomenology of Mental Imagery in People With Intellectual Disabilities

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Abstract

Objectives: Mental imagery is important in the development and maintenance of psychological disorders and wellbeing but has been neglected in people with intellectual disabilities. A detailed idiographic analysis of the lived experience of mental imagery in this population is presented.

Design: This qualitative study uses interpretative phenomenological analysis (IPA). It involved inclusive research methods with people with intellectual disabilities and other stakeholders (including family members, advocates, support workers and intellectual disability service managers).

Methods: Ten individual semi-structured interviews were conducted with people with mild–moderate intellectual disabilities. Participants were opportunistically sampled through organisations providing community services to people with intellectual disabilities in the UK. Two men and eight women (mean age 43 years) participated. Interviews were audio-recorded and analysed using IPA.

Results: People with intellectual disabilities are able to experience a range of rich and detailed mental images across all sensory modalities. Participants reported changes in affect based on mental imagery, and an ability to experience both spontaneous and deliberate mental images. The emotional saliency of the object of mental imagery appeared to influence participants' ability to engage with imagery. A number of adaptations make mental imagery more accessible and easier to report. The ability of people with intellectual disabilities to experience vivid mental imagery has important clinical implications for the use of a range of mental imagery interventions with this population.

Conclusions: The need to consider mental imagery interventions for this population, and how these can be adapted to ensure accessibility is a priority for people with intellectual disabilities and psychological disorders.

Practitioner Points

- People with intellectual disabilities can experience and engage with rich and vivid mental imagery across different sensory modalities.
- Specific techniques and strategies that facilitate or impede the use of mental imagery in people with intellectual disabilities are described.
- There are implications for using psychological interventions that incorporate mental imagery (e.g. imagery rescripting, generating positive images and metacognitive imagery-based interventions) with people with intellectual disabilities.

Keywords

Intellectual disability; Interpretative phenomenological analysis; Learning disability; Mental imagery; Phenomenology; Qualitative

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Conflict of Interest

All authors declare no conflict of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions

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Introduction

Mental imagery refers to the internal mental processes whereby perceptual information is accessed from memory (rather than directly from external stimuli) and is described as “seeing with the mind’s eye” although it can be experienced across sensory modalities (Kosslyn et al., 2006). Distressing or intrusive mental imagery is associated with the development and maintenance of various psychological disorders (Hackmann et al., 2011) including post-traumatic stress disorder and obsessive-compulsive disorder, and a lack of positive mental imagery is associated with depressive disorders (Holmes et al., 2016). Various mental imagery interventions have been developed to treat psychopathology, including for those with limited cognitive skills (e.g. Schwarz et al., 2020). People with intellectual disabilities experience higher rates of psychological distress than the general population (Cooper et al., 2007) and have limited access to evidence-based psychological interventions, partly due to their cognitive abilities (Tsimopoulou, et al., 2018).

Mental imagery abilities in people with intellectual disabilities are poorly understood. People with intellectual disabilities have difficulties with abstract thought, comprehending complex ideas, and verbal and communication skills (British Psychological Society, 2015). Mental imagery is complex and disentangling potential difficulties in experiencing imagery from verbal and communication difficulties in conveying such experiences poses challenges. However, a systematic review suggests people with intellectual disabilities experience all aspects (i.e., the generation, maintenance, inspection and transformation) of mental imagery, although may require scaffolding to report their mental imagery (Hewitt et al., 2021). This review identified a dearth of studies around the phenomenology of mental imagery in this population.

People with intellectual disabilities may experience less complex and vivid mental imagery (Brougham et al., 2020; Brown & Bullitis, 2006). Understanding how people with intellectual disabilities experience mental imagery has implications for the applicability of mental imagery interventions in this population.

Creating an image through drawing or collage, alongside verbal interviews, can elicit discussion and help researchers learn more about the phenomenon of interest (Gillies et al., 2005). People with intellectual disabilities can engage with qualitative research, including methods with a phenomenological stance (Rose et al., 2019). Whilst such research has been almost exclusively conducted solely through verbal interviews, Attard et al. (2017) note the constraints of language to convey the nuanced nature of some lived experiences, which is presumably amplified for people with intellectual disabilities. Integrating participant-created drawings within semi-structured interviews produced richer, deeper verbal data, with the images themselves providing useful information. Using self-created images is an attempt to listen for the rich, aesthetic “inner dimension” of the participants’ words (Todres 2007, in Attard et al, 2017), which provides an additional layer of meaning to be explored through interview and analysis. Images offer an additional information about the phenomenon and produce meanings independent of verbal material but can be used alongside verbal accounts to add depth and richness to our exploration of the phenomenon (Boden & Eatough, 2014). Therefore, visual and verbal data were gathered in the current study and analysed using Interpretative Phenomenological Analysis (Boden et al., 2019) to explore mental imagery amongst people with intellectual disabilities.

Aims of This Study

This study used verbal methods (semi-structured interview) and non-verbal methods (creating an image) to explore the lived experience of mental imagery in people with intellectual disabilities.

Method

Approach and Design

This qualitative study was designed and conducted from a phenomenological perspective. The project was developed via an inclusive research approach. This involved using coproduction with two separate groups, a group of people with intellectual disabilities (named the STAR Group), and a Stakeholder Group (comprising family members, advocates, support workers and intellectual disability service managers). Both groups were involved in the project conception, design, and analysis. Whilst neither group were directly involved in writing this paper, due to the iterative nature of their input throughout the research process, their voice forms part of the authorial voice.

The semi-structured interview schedule was co-designed with the STAR and Stakeholder Groups. A range of topics were gathered (from the literature, a systematic review, and discussion with clinicians working with mental imagery) and presented in accessible formats to the groups. Once topics for exploration in the interviews were agreed through group consensus, both groups were again consulted to discuss and agree experiential exercises to be included in the interview, and the format of the image participants would create. Adaptations to improve accessibility to the interview schedule were adopted.

Participants took part in one-to-one interviews. A favourable ethical opinion was given by a United Kingdom University Research Ethics Committee (Ref: 124/20-21) (see Appendix 4). Informed consent was obtained from all participants (see Appendix 5 for participant information sheets and consent forms).

Sampling

Participants were recruited through opportunistic sampling from community settings specifically serving people with intellectual disabilities (e.g. day centres, self-advocacy groups; Table 1). All participants were White British. Participants were excluded who did not have capacity to make a decision about whether they wished to take part in the study, were under 18 years of age, or had autism. Participants needed to be able to communicate verbally and describe their internal experiences of mental imagery.

Participants

The first author conducted individual interviews with ten people with mild to moderate intellectual disabilities on one occasion. Eight women and two men aged 25-54 ($M_{\text{age}} = 52.3$ years) participated.

Table 1

Participant Demographic Information

Pseudonym	Age	Gender	Ethnicity	Diagnoses	Living environment	Length of interview (minutes)
Clarissa	54	Female	White British	Mild ID	Residential home	54
June	43	Female	White British	Mild ID	Residential home	56
Bethany	48	Female	White British	Mild ID	Residential home	93
Peter	40	Male	White British	Mild ID	Shared lives placement	60

Anthony	48	Male	White British	Mild ID, dyspraxia	Family home	70
Zadie	46	Female	White British	Mild ID	Shared lives placement	51
Clemency	25	Female	White British	Mild to moderate ID	Supported living group home	48
Maria	30	Female	White British	Mild to moderate ID	Supported living group home	62
Karla	49	Female	White British	Mild to moderate ID, Down syndrome	Supported living group home	67
Rebecca	52	Female	White British	Mild ID, physical disability	Supported living group home	65

Data Collection

The semi-structured interview had three phases:

Phase 1 explored the concept of mental imagery. A verbal description of mental imagery was provided. Participants were guided through an adapted mental imagery exercise to practice using mental imagery (Hackmann et al., 2011). Their mental imagery abilities and experiences were further explored.

During Phase 2 participants created an image, through drawing and/or collage, to reflect their experience of mental imagery. They could recreate an image which had already been explored during phase 1 or choose a different image or memory to create using a selection of papers, art media (including pencils, biros, coloured pencils, felt-tip markers, chalk pastels, and acrylic paint), glues and a selection of magazines. Notes were taken on how participants approached the activity (Boden et al., 2019).

On completing their image, participants were guided to describe parts of the image, overall meaning, and the process of creating it, to illuminate the meaning of the image for the individual. Consideration was given to the anonymity of the images. Images were electronically copied, and participants kept the originals.

During Phase 3 the Vividness of Visual Imagery Questionnaire (Marks, 1973) was administered with prompts, to explore experiences of mental imagery.

Interviews lasted between 48 and 93 minutes ($M = 62$ minutes). Interviews were audio-recorded and transcribed verbatim with pseudonymisation to ensure confidentiality.

Data Analysis

Transcripts and created images were analysed using Interpretative Phenomenological Analysis (IPA; Smith et al., 2021). All co-researchers contributed to each stage of data analysis (both verbal and visual materials), alongside the academic research team. OH completed initial verbal data analysis, involving each transcript being read repeatedly, exploratory notes being made detailing descriptive, linguistic and conceptual comments, and experiential statements being compiled in each transcript, which were refined by seeking patterns and connections between them to develop super-ordinate themes (Smith et al., 2021). Individual transcripts were revisited with these themes in mind, in an iterative process to ensure each participant's voice was captured. Visual and verbal data were treated similarly (with the participant's own meaning making as primary, and with the researcher's interpretation also seen as important)

Data were presented to co-researchers throughout this process in accessible formats including the use of post it notes, single words and symbols to represent aspects of the data, as well as portions of transcripts being role played. Visual images were similarly analysed using the meaning participants made of their image, combined with a structured framework for visual data analysis (Boden et al., 2019).

Data analysis took place in small groups in-person and online and over multiple meetings. The Stakeholder Group met three times over four months (mean of 8 attendees, range 7-9). The STAR Group met four times over five months (mean of 7 attendees, range 4-13). Analysis was conducted during these meetings and during meetings with academic researchers, in an iterative process.

The STAR and Stakeholder groups conducted all stages of analysis including recording initial impressions, identifying initial themes, making changes to the structure of superordinate and subordinate themes, and choosing quotes to illustrate subthemes. The groups compared themes to find patterns across participants and develop the final set of themes. This was facilitated through using sticky notes to concretely represent themes from different participants which could be physically moved by group members. Discussions within the research team highlighted areas where the link between interpretative comments or themes and the raw data was less clear and allowed for consideration of how the researchers' own beliefs and preconceptions might influence analysis.

Quality assurance (Mays & Pope, 2020) was considered throughout this study. To ensure sensitivity to context, efforts were made during data collection to address the power imbalance between the researcher (OH) and participants with intellectual disability (e.g., starting with a brief general conversation to build rapport). To enhance rigour and transparency, an audit trail was documenting how themes developed for each participant and across participants was maintained. A reflective log was kept throughout the process.

Results

Table 2

Themes and Subthemes Identified by the Researchers

Superordinate themes	Subordinate themes
Theme 1: Mental imagery involves making, comparing, checking and changing images	Images can be clear and detailed
	Comparing different parts of an image
	Checking the details of an image
	Changing parts of an image
	Mental images can move
Theme 2: Our mental imagery can happen in any sense	Seeing mental images
	Touching mental images
	Hearing mental images
	Smelling mental images
	Tasting mental images
	Mental imagery can happen in more than one sense at the same time
Theme 3: Anything is possible in the world of mental imagery	Mental imagery can be surprising and funny
	Mental images can do impossible things vs mental images follow everyday rules
	We can share our mental images with other people
Theme 4: Mental imagery can have a big effect on our feelings	Mental imagery can give us strong feelings
	Mental imagery can make us feel lots of different feelings
	It can be easier or harder to imagine things that are important to us
Theme 5: Doing mental imagery can feel easy or difficult	Feeling like we're really good at mental imagery
	Sometimes mental imagery can feel too hard
	Asking us questions helps us have detailed mental imagery
	Helping us to concentrate makes mental imagery easier

Theme 1: Mental Imagery Involves Making, Comparing, Checking and Changing Images

All participants could engage with and explore mental imagery. The *clarity, detail* and richness of the images created and reported was notable. As well as creating mental images, participants described *changing* and manipulating these images. Participants could focus in or *check* details or *compare* aspects of an image. Most participants experienced several of these processes, suggesting an ability to manipulate and transform a *detailed*, malleable image, rather than experiencing flat, static mental images. Images could incorporate *movement* of objects, and participants seeing themselves *move* within an image. Such experiences conveyed a sense of imagery being under the participant's deliberate control.

Participants' mental imagery could be *detailed*, often including aspects of *movement* or being experienced in different sensory modalities. Peter spontaneously reported experiencing mental imagery in his everyday life, and during the interview he reported fluent, vivid and complex mental imagery without prompting:

I see the flowers, there's flowers and there's a big bird like a kite flying round and there's a tree beside me and it's summertime and it's really pretty, there's blue skies, the clouds, oh it's wonderful and it's relaxing to walk round. Oh, it's lovely, it's really lovely it makes me relax and makes me happy. It's really, really nice. I can see it as well. There's birds singing and it's wonderful. I can see rabbits and foxes.

Participants could 'zoom in' or focus on aspects of an image to *check* details, as June when inspected her image to report on the number of orange pips in a specific segment:

OH: How many pips have you got there?

June: Four.

Participants could hold an image in mind to *change* and *compare* aspects of it, which involved significant transformation of the image. Although June was asked to change the colour of her bedroom carpet, she went further than this, opting to change the material. She then used

imagery to experience the appearance and texture of the wooden floor across sensory modalities. The speed and fluency with which she described the new floor indicated the richness and accessibility of her imagery as well as the ease with which she performed this transformation:

OH: Imagine that green carpet that you've got... imagine that it changes colour.

June: Instead of a carpet, get a wooden floor.

OH: Yeah. Change that carpet to a wooden floor in your head, can you imagine that?

June: Yeah.

OH: Now when you were walking on that green carpet, it was feeling rough on your feet.

Now you've got a wooden floor...

June: Slippery!

The vividness of mental images included aspects of movement, as well as the ability to compare, change and check aspects within the image.

Theme 2: Our Mental Imagery Can Happen in Any Sense

Almost all participants experienced mental imagery across different sensory modalities. Reporting mental imagery in the *visual modality* appeared to be the easiest and most common experience initially. However, most participants could, with practice and feedback, access and report mental imagery in other sensory modalities and, for several participants, *across several sensory modalities simultaneously*. This experience points to the phenomenology of mental imagery for participants; whilst it is experienced as distinct from perceptual experiences, it is also experienced 'as if' real. This was conveyed to the interviewer both verbally and through participants' facial expressions and body language.

Zadie had not experienced mental imagery before the interview but quickly understood what was meant by the term and subsequently *experienced mental imagery*

across different sensory modalities simultaneously. When asked to imagine *tasting* an orange she declined to do so and instead, with the interviewer, built an alternative *visual* image of enjoying an ice cream at the beach. Several participants could use mental imagery flexibly, rather than simply following instructions from the interviewer. Zadie's ability to experience parts of the image as pleasurable (the *taste* of chocolate) whilst simultaneously finding other sensory aspects (the sticky *feeling*) unpleasant, and noting the *coldness* of the ice cream demonstrates the complexity and idiosyncratic nature of mental imagery:

OH: This chocolate ice cream...

Zadie: It's in a cone, with a chocolate flake and you lick it and it goes down in the cone really fast.

OH: And is it a bit melting this chocolate ice cream?

Zadie: Yeah. And I've got it all round my face and hands.

OH: How does it feel on your hands?

Zadie: Sticky and horrible.

OH: What does it taste like?

Zadie: Oh, lovely!

OH: And is it very cold the ice cream?

Zadie: Very cold.

Participants could experience rich and detailed imagery when reporting several aspects of a single sensory modality. Bethany was able, with prompting, to report several aspects of the *tactile* experience of her image, including the weight, texture and temperature of an imagined orange:

OH: What does it feel like?

Bethany: Cold.

OH: It feels cold, yeah.

Bethany: You can peel it off and start eating it.

OH: Yeah. Is it heavy or is it light, this orange?

Bethany: Heavy.

OH: It feels quite heavy. And what does the skin feel like, it feels cold, but is it smooth or bumpy?

Bethany: Smooth.

These quotes illustrate the ability of participants to experience vivid imagery across all sensory modalities, including *smell*, as Bethany later described “[it] smells of orange...it is a nice smell”. The ability to experience an image across several sensory modalities simultaneously was notable, as was experiencing different aspects of one sensory modality, both of which provided a vividness to the image.

Theme 3: Anything is Possible in the World of Mental Imagery

This theme encompassed a range of experiences whereby images could be *surprising*, *extraordinary* and *humorous*. Whilst in theme one participants’ mental

imagery could be predictably transformed, remaining under their control, this theme included unbidden, unexpected aspects of imagery. Examples of this included Maria discovering her imagined orange was rotten “No, it’s gone off, sorry...it’s bad for you, it will give you an upset tummy” and Peter spontaneously visualising “A big ball in my bedroom [laughs]...It’s like all different colours...It’s bouncing, bouncing, bouncing, bouncing all in my room”. The inclusion of movement in an image (often unexpected) gave a sense of the unpredictability of imagery, with it shifting and developing in different directions, seemingly only partially controlled by the participant.

A dichotomy of experiences emerged, whereby for some participants their *mental imagery abided closely by real life rules* (including their physical limitations and socially constructed rules around Covid restrictions). One participant with dyspraxia couldn’t imagine catching an orange due to their physical limitations. Karla’s *mental imagery abided by the real-life rule* of wearing a face mask, preventing her from eating an orange: “I can’t feel...I can’t eat it with my mask.”

However, for several participants, *mental imagery could be used to do impossible things* such as journeying into space. Maria was especially interested in unicorns, as reflected in her created image and her interview. With little prompting, and a sense of this image unfolding in her mind’s eye, she fluently described a magical nightscape:

OH: Imagine the sun going down in the evening...

Maria: It’s shining and it’s yellow and bright and the moon is out and all the stars are out and all the lovely stars are twinkling in the sky and the moon is full, a full moon and a happy moon, not a sad moon. And he’s got his eyes shut, it’s

bedtime and the stars are out twinkling down and the sun is...and the sun is awake because it's night time and it's yellow due to the sunshine, and then that's it. And the stars have unicorns around it; all round the stars are unicorns.

For such participants mental imagery could be used to explore *impossible scenarios* and was not *restrained by the everyday*. They had a confidence and fluency around experiencing and reporting such imagery.

Several participants used noise and gestures to convey their mental imagery to the interviewer, acknowledging that whilst mental imagery is an intrinsically internal experience, it can also *be shared with others*:

OH: What noise are the waves making on the beach?

Clarissa: Shshshsh. Beautiful!

OH: And it's quite breezy. And can you hear any seagulls?

Clarissa: Yeah... [makes squawking noise]

OH: And are the dogs playing in the water?

Clarissa: Yeah, they're barking away.

This elicitation of imagery required a *shared*, relational space to be created between the interviewer and participant. Whilst imagery was generated within the participants internal world, the process of communicating with the other, and being prompted by the ideas and suggestions of the interviewer, led to a collaborative and iterative process of further *sharing* and elaboration of imagery.

This theme encompasses the wide range of mental images experienced by participants. Whilst engaging with mental imagery was both personal and idiosyncratic, it could be shared with others and include playful, unexpected aspects.

Theme 4: Mental Imagery Can Have a Big Effect on Our Feelings

Almost all participants described changes in affect linked to experiencing mental imagery. Changes in feelings could be *strong* and powerful, and encompassed a *wide range of different emotions*, such as surprise, delight, disgust and fear. They were communicated both verbally and nonverbally (e.g. through changes in facial expressions, voice), which conveyed the *intensity* of these emotional responses. When experiencing mental imagery, participants could describe their *associated emotions*, and respond to emotional reactions ‘as if’ they occurred in real life (e.g., exploring details of pleasurable images or avoiding feared situations within mental images). Zadie demonstrated a *range of emotional* and behavioural responses to mental imagery including exploring pleasurable images in different sensory modalities:

OH: So let’s imagine...on your bedside table there’s a really big, lovely bunch of flowers.

Zadie: Oh, that would be lovely! Red, yellow, pinks, oranges, all different colours.

OH: What do they smell like?

Zadie: Really, really nice, with a nice vase.

Conversely, other images prompted anxiety, and associated behaviour change:

Zadie: There’s gonna be a big thunderstorm... All the clouds come, they’re getting closer and closer...and I’m a bit scared so I go to my room and hide under the duvet.

Participants' ability to engage with mental imagery around emotionally salient items varied in unpredictable ways. Participants found it *both easier or harder to imagine things that were important or held emotional significance*.

For some, focusing on a familiar and loved object, such as a pet, facilitated their ability to generate mental imagery. However, asking people to engage with mental imagery around other precious items could impede imagery as people protected these items from perceived harm or disrespect. For several participants, the *strength of affect* generated was noticeable. Clarissa spoke about her neighbour's cat Marley throughout her interview. She was very fond of the cat and generated, developed and transformed mental images of it. Subsequently, however, imagining Marley impeded her mental imagery. Marley was not allowed in Clarissa's house, and when asked to imagine Marley in her bedroom she had a *strong emotional response*:

Clarissa: Ergh! That's horrible. I wouldn't allow it.

OH: You don't like it do you? I can see from your face.

Clarissa: She wouldn't be allowed upstairs. She wouldn't be allowed up there.

Another example of the impact of the emotional saliency of objects of the participant's ability to incorporate them into mental imagery occurred when Clarissa was asked to imagine herself jumping on her bed:

OH: Get on the bed and start jumping up and down! Can you imagine?

Clarissa: No!

OH: Just imagine that in your head.

Clarissa: It'll break it....

OH: Can you imagine doing it?

Clarissa: Nope.

OH: Can you imagine me doing it?

Clarissa: No!

It transpired the bed was a gift from Clarissa's parents and she was reluctant to treat this precious item disrespectfully.

Understanding the idiosyncratic links between the emotional saliency of an object and the impact this may have on a persons' ability to engage with mental imagery around it can be subtle, requiring careful exploration.

Theme 5: Doing Mental Imagery Can Feel Easy or Difficult

Participants experienced a continuum of mastery over mental imagery. For some, mental imagery across different sensory modalities *was a pre-existing skill they could effortlessly engage in*. For example, Peter frequently spontaneously reported complex mental imagery across sensory modalities in a fluent and eloquent manner, reflecting the ease with which he experienced and could report these phenomena. For others it was an untapped resource, they were initially unaware of but could quickly and easily engage with through practice and receiving feedback on the imagery exercises in phase one. However, for a few participants mental imagery remained challenging to engage with throughout the interview, and they required additional prompting and scaffolding to experience any mental imagery.

Even with various strategies to support participants' engagement, almost all participants found some aspect of *mental imagery was too hard* or inaccessible. Such aspects varied between participants, although several participants found transforming images more difficult than generating new images or inspecting or checking existing mental images. Zadie struggled to change an image of an orange into a frog:

OH: Do you find it easy to do or hard?

Zadie: Some of it's a bit hard.

OH: Which bits have been hard?

Zadie: Well, the one you said about the frog.

Various techniques facilitated the development of mental imagery. Reducing external, environmental distractions and *improving concentration* was helpful (e.g. suggesting participants close their eyes). *Asking both open and closed questions* helped participants reflect on their images and develop them further. Scaffolding, which included repeating back descriptions of images, encouraged elaboration. Whilst providing additional prompts and scaffolding generally helped all participants to provide more detailed imagery, it was essential to help some engage with and report mental imagery. Clemency's level of verbal fluency and cognitive skills were somewhat lower than other participants. Whilst she *struggled to describe and report her mental imagery* to others at points in the interview, she could generate imagery in different sensory modalities relatively easily:

OH: What do the mountains look like?

Clemency: They are white.

OH: Why are they white?

Clemency: Because it's got snow.

OH: They are very big mountains.

Clemency: Don't like snow!

OH: You don't like snow?

Clemency: Cold.

Whilst all participants could engage in mental imagery to some extent, the aspects of mental imagery they found easiest varied. For some this was related to the emotional saliency of an object, whilst others found particular aspects of manipulating images difficult. Other could access mental imagery in specific modalities more easily.

Discussion

A phenomenological approach was used to explore experiences of mental imagery in people with intellectual disabilities. Participants reported rich, detailed mental images, which could be surprising, spontaneous, elicit emotions and experienced across sensory modalities. Their experiences creating, comparing, checking and changing mental images map onto theoretical aspects of mental imagery generation, inspection, maintenance, transformation (Kosslyn et al., 2006), and manipulation (Pearson et al., 2013). The only unrepresented theoretical stage was image maintenance, which occurs at a neural level.

All participants could engage with and report some aspects of mental imagery. There were many similarities with experiences of mental imagery within the general population. Whilst Brougham et al. (2020) reported that adults with intellectual disabilities can generate a compassionate image similarly to those without intellectual disabilities, Brown and Bullitis (2006) found only half of people with intellectual disabilities clearly experienced mental imagery. The current study indicated that adults with mild-moderate intellectual disabilities experience vivid, detailed mental imagery.

Participant's ability to experience mental imagery simultaneously across several sensory modalities indicates the complexity and richness of mental imagery experienced. The multi-sensory nature of mental imagery was prompted for and facilitated through the semi-structured interview. Previous research suggested that whilst participants with intellectual disabilities commonly experience visual mental imagery, fewer than half experienced tactile, olfactory, gustatory or kinaesthetic imagery even when specifically prompted (Brown & Bullitis, 2006).

Mental imagery could be surprising for participants as well as the interviewer. Several participants did not recognise the concept of mental imagery and denied ever experiencing mental imagery including daydreams (as found by Brown & Bullitis, 2006). This is commonly found within the general and clinical populations and is why mental imagery should be specifically asked about at assessment (Hales et al., 2014), rather than relying on spontaneous self-report. However, participants willingly attempted various mental imagery exercises and could engage with such tasks. They seemed both pleased and surprised and occasionally would check they had retained this skill after the interview. Mental imagery could be unexpected, as when mental images transformed spontaneously. Mental imagery is both unbidden and deliberately constructed in the general population (Pearson et al., 2015).

Several participants spontaneously shared their internal experience of mental imagery with the interviewer, through consulting with them about changing their image, and using physical (gesturing the shape of a rainbow) or auditory (making the noise of a seagull) cues. Participants shared their internal experiences with the interviewer to build rapport and used mental imagery as a relational tool.

Engaging with mental images elicited a range of powerful emotions including joy, disgust and fear, as found in the general population, and people undergoing psychological interventions (Skottnik & Linden, 2019). Brown and Bullitis (2006) reported several participants declined to image actions such as climbing a stepladder (due to fear of heights), concluding that mental imagery elicits associated emotions in people with intellectual disabilities. Such findings are in line with Pearson et al. (2105) who found that visual mental imagery activates the same neural circuits as perceptual information, but in a weaker form.

The emotional saliency of items could both facilitate and impede a participant's engagement with mental imagery. Participants engaged more willingly with preferred objects, although not universally, as when a participant imagined a much-loved cat going into her bedroom (unallowed) and experienced a visceral reaction of outrage. Understanding why and when participants engage with various imagery is essential, as it may be erroneously assumed that not engaging with imagery is due to cognitive difficulties. Mental imagery can be emotional (as in this example) or non-emotional (e.g. mentally rotating an abstract figure) (O'Donnell et al., 2020). The lack of meaningful, emotionally salient stimuli used in mental imagery tasks comparing the performance of people with intellectual disabilities with aged-matched controls (e.g. Meneghetti et al., 2018) may partially account for poorer engagement and performance from people with intellectual disabilities.

The ease and mastery with which participants engaged in mental imagery existed on a continuum. Whilst all participants could engage in some mental imagery, most required scaffolding to build detail, in line with Brougham et al. (2020). However, a

couple of participants who provided detailed mental imagery without prompting, reported frequent, spontaneous mental imagery in everyday life. For several participants, mental imagery was difficult to generate and explore, requiring frequent prompting. The general population experience a range of mental imagery abilities, with a small proportion experiencing aphantasia (no mental imagery) (Keogh & Pearson, 2018). Level of cognitive ability did not seem related to mastery over mental imagery, with some of the more cognitively able participants struggling with this.

Within the general population people can be reluctant to report mental imagery, for example fearing it to be a sign of ‘going mad’ (e.g. Hales et al., 2014). Such reticence is overcome through detailed explanation of mental imagery and developing the therapeutic relationship. That participants in this study attempted mental imagery willingly may be partly due to providing a clear explanation of mental imagery and additional time developing rapport within the interview.

There is little evidence that mental imagery in people with intellectual disabilities differs substantially from the general population, with a recent systematic review concluding that “people with intellectual disabilities have similar mental imagery to other people, although it may be less vivid or complex.” (Hewitt et al., 2021). This study suggests that with adaptations, the mental imagery reported by people with intellectual disabilities can be as vivid and accessible as in the general population. Therefore, adapted mental imagery interventions for psychological distress (such as imagery rescripting, positive image generation etc) should be considered for this population. Indeed, rich mental imagery is found in other groups with cognitive limitations such as

very young children, (Burnett Heyes et al., 2013), making mental imagery-based clinical therapies suitable in such populations.

Various strategies facilitated mental imagery. Participants needed to clearly understand the task presented. Co-producing this project with people with intellectual disabilities and stakeholders helped ensure materials were accessible. Participants, especially those experiencing mental imagery for the first time, required feedback to know they were completing a task correctly. Providing prompts and questions helped participants scaffold and develop their answers and elicited richer imagery. Taking time to build rapport was essential in developing their willingness to engage with mental imagery exercises. The interviewer is a clinical psychologist with many years' experience of working with people with intellectual disabilities, which may have optimised participants' engagement. Minimising external distractions facilitated mental imagery, and whilst some participants found closing their eyes helpful (to aid concentration and reduce competing visual stimuli), this was difficult for some participants with physical disabilities. The individual areas of strength and skills regarding mental imagery required careful exploration with participants, using a curious, non-judgmental stance to optimise participants' abilities to engage in mental imagery. Several participants found incorporating movement into mental imagery challenging. For others, aspects of imagery transformation (such as in an imagery rescripting exercise) was hard. Understanding which aspects of imagery challenge an individual will be important when exploring mental imagery interventions with people with intellectual disabilities, as is providing practice and feedback on different types of mental imagery exercises.

This study employed an inclusive research approach (Frankena et al., 2019). People with intellectual disabilities, and (separately) stakeholders were involved throughout the project, except for data collection and disseminating findings (although a detailed dissemination plan has been made). All co-researchers were paid for their time.

Whilst co-researchers with intellectual disabilities are increasingly involved with qualitative data analysis (Di Lorito et al., 2018), there have been no reports of this with IPA data to our knowledge. Adaptations to make data analysis accessible included academic researchers identifying and role-playing portions of interviews and asking co-researchers for their reflections, reading out quotes, using plain English to describe themes, and asking people to reflect on their position when engaging in analysis (Cluely et al., 2021), thus helping everyone to understand why they might notice something different in the data based on their own personal experiences (i.e. drawing out the researcher's interpretations, and the meaning they make from this).

Limitations

Only participants from a white British background were recruited, limiting the experiences captured. All participants had mild-moderate intellectual disabilities. Directly including participants with severe and profound intellectual disabilities in research is challenging (Maes et al., 2021) and compounded when studying internal cognitive processes such as mental imagery. The parents and carers of several people with severe and profound intellectual disability were part of the stakeholder group.

Theme one maps closely onto the Kosslyn et al.'s (2006) model of mental imagery. The first author's familiarity with this model will have inevitably influenced their analysis, as will their position as a clinical psychologist working therapeutically with people with intellectual disabilities to explore their psychological experiences. The link between themes and verbatim quotes was emphasised throughout analysis. Involving different members of the research team in the analysis (including people with intellectual disabilities and stakeholders) ensured analysis was embedded in the data. Using supervision and a reflective log has supported this.

Implications

The ability of people with intellectual disabilities to experience and report complex mental imagery suggests that a range of mental imagery interventions may be appropriate for this population. However, a recent review of CBT interventions within this population found no use of mental imagery interventions (Hronis, 2021). Further work should identify, adapt and test mental imagery interventions for prevalent mental health conditions (e.g. anxiety) within this population.

Using meaningful stimuli in mental imagery tasks and developing good rapport with participants with intellectual disabilities is essential for engagement, in both clinical and research settings. Flexibility in the type of mental imagery intervention used, and how this is presented to people with intellectual disabilities, will be key in promoting successful engagement.

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Chapter 5

Using Experience Based Co-Design to Develop a Novel Psychological Intervention with People with Intellectual Disabilities and Stakeholders

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Abstract

Background: Psychological interventions need to be adapted for use with people with intellectual disabilities to ensure they are engaging, accessible and effective. Co-design allows the experiences of service users and stakeholders to be actively involved in shaping and developing interventions, to ensure their accessibility.

Method: An adapted model of Experience Based Co-Design (EBCD) was used to co-develop a novel, mental imagery based psychological intervention for people with mild to moderate intellectual disabilities and anxiety. Involvement in EBCD was evaluated for people with intellectual disabilities and stakeholders using both quantitative and qualitative methods.

Results: Numerous concrete and specific intervention adaptations arose and were implemented. Our findings indicated that all participants were able to engage fully with EBCD which participants found positive.

Conclusions: EBCD has likely resulted in a more accessible and engaging intervention which can be now tested within a larger study.

Summary

- We wanted people with intellectual disabilities and stakeholders to design a new treatment for anxiety.
- They came to some focus groups and a workshop and gave lots of ideas to make the treatment better.
- They enjoyed taking part in the research and being heard.
- We think their contribution made the treatment easier for people to understand.

Keywords

Co-design, Experience Based Co-Design, Mental health, intervention, anxiety.

Acknowledgements

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Ethics Statement

A favourable ethical opinion for this phase of the project was provided by the Humanities and Social Sciences Research Ethics Committee, University of Warwick (HSSREC 124/20-21) (see Appendix 4).

Consent

All participants in the project provided written, informed consent to participate prior to their inclusion in the project.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions

CRediT Statement:

Olivia Hewitt: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft

Peter E. Langdon: Conceptualization, Methodology, Supervision, Writing – review & editing

Michael Larkin: Conceptualization, Formal analysis, Methodology, Supervision, Writing – review & editing

Introduction

People with intellectual disabilities face numerous health inequalities (Emerson, 2021) and rates of mental health conditions are several times higher than in the general population (e.g., Hughes-McCormack et al., 2017; Buckles et al., 2013). Higher rates of anxiety disorders are seen across people with intellectual disabilities of mixed aetiology, with even higher rates in syndromic intellectual disabilities (Edwards et al., 2022).

Despite this, developing accessible, effective psychological interventions for this population has been challenging, with careful adaptations needed to ensure people can access treatments. Most psychological interventions, such as cognitive behavioural therapy (CBT), require adaptation for people with intellectual disabilities, and there is evidence to support their use. For example, systematic reviews and meta-analyses indicate that CBT is likely an effective intervention for anger and depression in people with intellectual disabilities (e.g. Cooper et al., 2016; Vereenoghe & Langdon, 2013; Tapp et al., 2023), but the literature is fraught with methodological bias limiting the certainty of such a conclusion. There are few controlled studies evaluating CBT for anxiety in people with intellectual disabilities with much of this literature consisting of small studies with methodological weaknesses (Unwin et al., 2016; Dagnan et al., 2018a).

CBT approaches for people with intellectual disabilities are often adapted to focus on behavioural, rather than cognitive strategies to reduce the reliance upon “talking” therapy components. The cognitive limitations of people with intellectual disabilities may make some cognitive techniques (e.g. identifying and altering core

beliefs) less accessible, as they require sophisticated metacognitive and verbal skills (e.g. Tsimopoulou et al., 2018). Interventions for mood disorders (such as anxiety) may also focus on behaviour management strategies rather than adapting internal cognitions (Acton et al., 2023), as changes in behaviour can be more easily identified by others.

Traditional CBT approaches have focused on verbal rather than visual cognitions (mental imagery). Mental images are internal mental processes whereby perceptual information is accessed from memory, rather than directly from external stimuli. They can occur in one or more sensory modality and have been described as “seeing with the mind’s eye” or “hearing with the mind’s ear” and so on (Kosslyn et al., 2006). Distressing or intrusive mental imagery is associated with the development and maintenance of various psychological disorders (Hackmann et al., 2011), and various mental imagery interventions have been developed to treat psychopathology, including amongst those with limited cognitive skills (e.g. Schwarz et al., 2020). These techniques include imaginal exposure and systematic desensitisation, imagery rescripting, guided imagery, and promoting positive imagery (Holmes & Matthews, 2010). Whilst mental imagery interventions form a core part of psychological treatments for disorders (including anxiety disorders), they have not yet been adapted or investigated for use with people with intellectual disabilities.

Co-design is increasingly being used within mainstream services to develop new interventions and to improve clinical services (e.g. Masterson et al., 2022). It aims to develop a detailed understanding of how an intervention is experienced by service users and stakeholders, thus allowing barriers to engagement, and other issues around

acceptability and accessibility to be identified and ameliorated at the design stage (Williamson et al., 2021). However, co-design is costly (in terms of time and resources) when conducted with people who have or do not have intellectual disabilities (Hewitt et al., 2023). Whilst co-production is increasingly being used to develop complex interventions (Smith et al., 2022), only one psychological intervention to date has been co-produced with people with intellectual disabilities (Acton et al., 2023). Other psychological interventions for anxiety amongst people with moderate to severe intellectual disabilities have been developed collaboratively with clinicians and carers (Langdon et al, 2024; Langdon Apanasionok, Scripps, Bunning et al., 2024).

Various models of co-design have been developed. Within mental health services, Experience Based Co-Design (EBCD) has been used to co-develop new services (Hawke et al., 2024) and adapt psychological and behavioural interventions for various physical and mental health conditions including perinatal depression (Pinar et al., 2022) and those surviving critical physical illnesses (da Silva, 2023). EBCD has been used to improve services for people with intellectual disabilities (e.g. Dimopoulos-Bick et al., 2019), and adaptations have been made to reduce the power imbalance, and to accelerate the EBCD process (Heerings et al., 2022).

Recently, Green et al. (2020) suggested EBCD could be employed to design complex research interventions, increasing intervention person-centredness and successful implementation. Fylan et al. (2021) produced a comprehensive protocol for using EBCD for intervention development and evaluation. Therefore, EBCD was the methodology we chose to co-design a novel, mental imagery based psychological intervention for anxiety in people with mild to moderate intellectual disabilities. In

developing this intervention, much of the guidance suggested by Flyan et al. (2021) has been followed but only the intervention design phase is described within this paper. Subsequent phases, including the intervention user testing and refinement phases are currently being conducted alongside people with intellectual disabilities and stakeholders; our findings will be reported in the future. Our focus here is upon describing the use of an adapted version of EBCD to design the intervention for use with people with intellectual disabilities. Additional changes were required when using EBCD to ensure that the process was meaningful and accessible which are described in this paper.

Aims

This paper aims to (a) describe how EBCD was adapted to co-design an intervention with people with intellectual disabilities and stakeholders, (b) describe the resulting intervention refinements made to meet the needs of people with intellectual disabilities, and (c) understand the experiences of participating in EBCD and consider whether this methodology was acceptable and accessible for all participants.

Method

Participants

Two groups of participants were recruited: (1) a group of stakeholders, made up of family members, health and social care professionals, service commissioners, advocates and those working directly with people with intellectual disabilities in support roles. Stakeholders included people who had been involved with previous phases of the wider research project, and those who with no previous involvement, and (2) a group of people with mild to moderate intellectual disabilities (some of whom had

been involved in previous aspects of the project, and some had had no prior involvement). Both stakeholders and people with intellectual disabilities were recruited through community groups such as self-advocacy groups, and community projects.

Inclusion criteria for the group of stakeholders were: (a) self identifies as someone who is a stakeholder for people with intellectual disabilities and services provided to support them, (b) provides informed consent to participate, and (c) has adequate English language skills to participate in interviews and discussions. Exclusion criterion for the group of stakeholders was being unable to provide informed consent to participate in the study.

Inclusion criteria for the group of people with intellectual disability were: (a) diagnosis of mild or moderate intellectual disability, (b) self identifies as someone with a mild or moderate intellectual disability and is recruited through services specifically for people with intellectual disabilities, (c) has adequate English language skills to participate in interviews and discussions, (d) is able to provide informed consent to participate in the research, and (e) is aged 18 years or older.

Exclusion criteria for the group of people with intellectual disability were (a) having a diagnosis of severe or profound intellectual disability, (b) known to have been assessed as not having an intellectual disability or has been refused access to health or social care services for people with an intellectual disability, (c) aged under 18 years, or (d) unable to participate in verbal interviews.

The group of people with intellectual disabilities included those with various additional physical and sensory needs, and some with personal experience of mental health difficulties and receiving psychological interventions. Two potential participants approached the research team via email to request participating as a member of the

group of people with intellectual disabilities. The research team clarified the inclusion criteria of having a diagnosed intellectual disability with these individuals, who did not make further contact with the research project.

While participant's level of intellectual disability was not assessed to establish a diagnosis of mild or moderate intellectual disability, only participants who were currently, or had historically receiving a service from the community learning disability team were included. The team would have previously determined that each participant had a learning disability and therefore it was not necessary for the research team to repeat this process. People with a severe or profound intellectual disability were excluded from the study as they were unable to provide informed consent to participate.

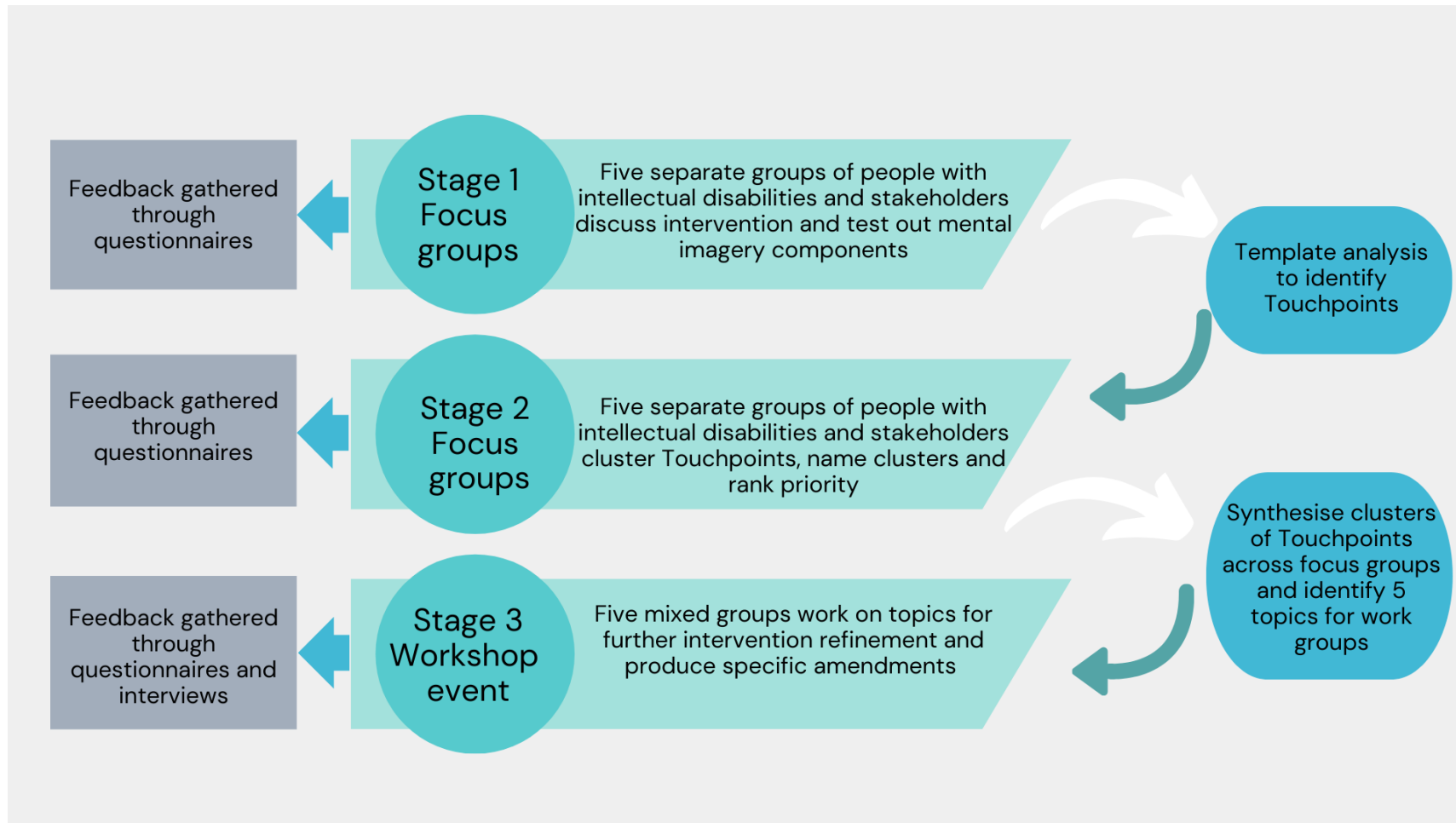
Participants could be involved in one or more focus group (Stage 1 and Stage 2) and /or the workshop event (Stage 3) (see Figure 1).

A total of 61 individuals took part across all three stages of the project. All participants in Stage 1 and 2 focus groups were paid £10 to thank them for their time. No payment was made for Stage 3 attendance due to budgetary constraints. All participants in the project provided written, informed consent to participate prior to their inclusion in the project. A favourable ethical opinion for this phase of the project was provided by the Humanities and Social Sciences Research Ethics Committee, University of Warwick (HSSREC 124/20-21).

Table 1 details demographic information for the participants involved in each stage of the EBCD process.

Figure 1

The Three Stages of the Experience Based Co-Design Process



Design and Procedure

Before embarking on the process of EBCD, the research team set three parameters to the intervention that was to be developed. This was required to present participants in the EBCD process with materials and examples of potential aspects of the intervention that could be included or adapted. One way we made EBCD accessible for people with intellectual disabilities was to present ideas and examples of potential aspects of the intervention (e.g. different outcome measures, examples of mood recording sheets, examples of mental imagery interventions) that could be included or amended. Asking people to design such materials from scratch or be aware of existing materials that could be included would be too time consuming and complicated.

The three parameters were that the intervention should be accessible for people with mild to moderate intellectual disabilities, target symptoms of anxiety, and be based on one or more mental imagery components. People with severe and profound intellectual disabilities are unable to access talking interventions, and therefore we did not require the intervention being developed to be accessible to these groups of people. Additionally, we do not know what experiences of mental imagery people with severe and profound intellectual disabilities can experience, manipulate and report. Anxiety was chosen as the focus of the intervention because it is common in people with intellectual disabilities, and because people with anxiety disorders have more frequent and accessible mental images than in other mood disorders (Ng et al., 2015). A novel aspect of the intervention was that it should be based on mental imagery interventions, as previous work (Hewitt et al., 2022; Hewitt et al., 2023) indicated that these may be effective and accessible methods to shift affect in people with intellectual disabilities and mood disorders. Therefore, examples of three different

Table 1*Demographic Information for Participants*

	Stage 1 focus group	Stage 1 focus group	Stage 1 focus group	Stage 1 focus group	Stage 1 focus group	Stage 2 focus group	Stage 2 focus group	Stage 2 focus group	Stage 2 focus group	Stage 2 focus group	Stage 3 workshop
Number of people with Intellectua l Disability	N=3	N=3	N/A	N/A	N/A	N=3	N=4	N=3	N/A	N/A	N=16
Additional diagnoses	Compl ex PTSD	Epileps y, anxiety	N/A	N/A	N/A	Compl ex PTSD	Deaf, epileps y, anxiety	Anxiet y	N/A	N/A	Epilepsy, complex PTSD, anxiety, deaf, cerebral palsy,
Age range	43-54	25-48	38-44	N/A	N/A	43-54	25-56	18	N/A	N/A	22-63
Ratio F:M	3F	2F:1M	2F	N/A	N/A	3F	2F:2M	2F:1M	N/A	N/A	F12:M4
Number of stakeholde rs	N/A	N/A	N=2	N =3	N = 4	N/A	N/A	N/A	N = 5	N = 5	N = 32
Role	N/A	N/A	Learning disability nurse, commission er	Day service manager, family member, clinical psychologi st	Clinical psychologi st, researcher, family member	N/A	N/A	N/A	Learning disability nurse, commission er, day service manager,	Advocate, researcher, clinical psychologi st, family member	Clinical Psychologi st, family member, support worker, day services manager,

									family member		researcher, educational worker
Age range	N/A	N/A	N/A	41-62	24-43	N/A	N/A	N/A	27-62	25-53	Age 20-83
Ratio F:M	N/A	N/A	N/A	2F:1M	4F	N/A	N/A	N/A	4F:1M	4F:1M	27F:5M

types of mental imagery interventions were chosen to be presented through the EBCD process. These specific mental imagery interventions were chosen because they have a good evidence base in mainstream populations, have clear mechanisms of change described in the literature and are underpinned by a robust psychological theory, and could be easily adapted to be accessible for people with mild to moderate intellectual disabilities. The interventions were chosen after discussion within the research team and through consulting expert clinicians who deliver mental imagery interventions to other client groups. The mental imagery interventions that were selected were generating positive images (Brougham et al., 2020), the attention training technique (Wells, 1990) and changing the properties of an image (based on imagery rescripting exercises; Holmes et al., 2019). The types of mental imagery manipulation required by each mental imagery component was also considered. It was hoped that by including relatively simple mental image exercises such as generating an image (as in generating positive images and the attention training technique), as well as exercises which required several mental imagery processes such as generating, inspecting and transforming an image (such as changing aspects of an image), we would have imagery components that would be accessible to individuals with a range of mental imagery abilities. It was expected that one or more of these mental imagery components would be selected and adapted for inclusion in the intervention through EBCD.

No other parameters were set before the EBCD process, leaving scope for the intervention to be developed in a myriad of creative ways, depending on the input from EBCD participants. Despite the constraints of the three parameters that had been set, participants within the EBCD process continued to provide feedback and reflections on

how these limitations may be addressed in future work, which are considered within the discussion section.

There are detailed and well-established guidance for using EBCD as a quality improvement tool (for example through The Point of Care Foundation). As mentioned earlier, Fylan et al. (2021) provide details of how EBCD can be integrated into intervention development and evaluation. Within this project, our priority was for the EBCD process to be accessible and meaningful for people with intellectual disabilities, as well as stakeholders. Therefore, Table 2 details the phases of EBCD as used for intervention development (Fylan et al., 2021) and the adaptations made within this project to ensure accessibility for people with intellectual disabilities. These were based on literature describing how best to adapt psychological interventions for people with intellectual disabilities (Witwer, 2022), the clinical experience of the research team in working with this client group, and previous research phases including a systematic review of mental imagery in people with intellectual disabilities (Hewitt et al., 2023) and a phenomenological study into the experience of mental imagery in people with intellectual disabilities (Hewitt et al., 2023).

Stage 1

Initially a series of five focus groups were conducted, each lasting around 1 hour. Three focus groups consisted of stakeholders, and two of people with intellectual disabilities. Each focus group was facilitated by a clinical psychologist with 17 years' experience of working clinically with people with intellectual disabilities. The facilitator was able to use open ended questions as well as prompts and examples to ensure that participants understood the information being presented to them. Building a good working relationship with participants ensured they felt able to express uncertainty and

Table 2*Adaptations to Intervention Development EBCD Processes Made in This Project*

<u>EBCD intervention development stage and purpose (Fylan et al (2021))</u>	<u>Adaptations made in current project</u>
	• Generic adaptations to improve accessibility, such as: • Taking extra time to explain the context of the project and the task participants were being asked to complete at each stage of the project, • Using visual aids to help explain concepts. • Building rapport and allowing extra time to do this. • Emphasising that there are no wrong or right answers and that all feedback is welcomed • All facilitators had clinical experience of working with people with intellectual disability • Ensuring meetings took place in a familiar, convenient and accessible location. • Meeting people in a venue they felt comfortable i.e. for one focus group we met at a day centre as this was the most convenient location for everyone.
Stage: Participant training (as an event or distributed in stages) Purpose: To inform and engage participants and investigators with respect to EBCD	Information and training around EBCD were provided to stakeholders and people with intellectual disabilities separately. Smaller amounts of information, targeted to be directly relevant to the current EBCD stage, were provided regularly (every 6-8 weeks) throughout the project. Sessions were provided face to face for people with intellectual disabilities and online for stakeholders to improve accessibility.
Stage: Exploratory research Purpose: To understand the lived experience of patients, their supporters or carers and providers	A formal qualitative study using Interpretative Phenomenological Analysis (Hewitt et al, 2023) had previously been conducted into the mental imagery experiences of people with intellectual disabilities. A systematic review of mental imagery in people with intellectual disabilities had been conducted (Hewitt et al (2023). Results from both of these studies fed into the EBCD project. Stage 1 - Separate focus groups were conducted with small groups of people with intellectual disabilities and stakeholders to explore their experiences of undertaking various aspects of the intervention.

	Focus groups were deliberately kept small (3-4 participants with intellectual disability) to allow plenty of time and space for everyone to participate, and so a higher level of facilitation could be provided if required These were formally analysed using Template Analysis, synthesised across both groups and touchpoints identified. Touchpoints were refined to reduce duplication, simplify the language used and ensure each touchpoint contained only one concept.
Stage: 'Trigger film' production Purpose: Create a 'trigger film'. This is a short video which summarises key salient moments (touchpoints) from a patient and carer perspective	This was completed after Stages 1 and 2 and before Stage 3. The trigger film consisted solely of people with intellectual disabilities, who interviewed each other about the emotional touchpoints of the project, their experiences of anxiety, and the consequences of untreated mental health conditions on their everyday life.
Stage: Patient and carer event. Purpose: First showing of trigger film to patients and carers, discuss priorities for service improvement	Stage 2 - A further series of small focus groups were held with people with intellectual disabilities separately to cluster the identified touchpoints into areas for intervention refinement. These areas were then ranked in order of priority for change. Facilitators had flexibility so that if required, they could provide extra support and guidance to the groups of people with intellectual disabilities when they were clustering and prioritising touchpoints, as this was felt to be a challenging task. However, these groups coped very well with the task, and generated their own strategies to help complete the task, such as using a pen to highlight key words on each touchpoint which helped them to cluster similar ideas.
Stage: Professional event Purpose: Discuss priorities for service improvement with providers	Stage 2 - A further series of small focus groups were held with stakeholders separately to cluster the identified touchpoints into areas for intervention refinement. These areas were then ranked in order of priority for change.
Stage: Joint event Purpose: Second showing of trigger film to all stakeholders, discuss priorities for service improvement	Stage 3 - The joint workshop event was held at an accessible community venue. This included the first showing of the trigger film. Priorities for intervention refinement had been established in Stage 2 focus groups, to allow people additional time and smaller groups in which to complete this task. Therefore, the areas for intervention refinement had already been identified ahead of the workshop, allowing for careful planning regarding the makeup of each small group. This

	ensured everyone had the necessary support to be able to engage with the task (e.g. familiar support worker in same group).
Stage: Design groups Purpose: Develop solutions for the identified service improvement priorities	Stage 3 - During the workshop mixed groups of participants worked in small groups to develop solutions regarding five different areas for intervention refinement. Extensive feedback on the planning of the workshop was sought from all potential participants to ensure the day was as accessible as possible. We ensured that each small work group had at least two (and usually three or four) people with intellectual disabilities on each table, so no one individual was responsible for providing the lived perspective of having an intellectual disability. People were welcome to bring a supporter and could also specify if they wished to be in the same group as their supporter. Each group was provided with an accessible task (with minimal literacy skills required) that prompted discussion and solution generation for each area of intervention refinement. Alternative formats to written exercises, such as role plays, pictures or symbols were used. Similarly, feedback could be provided in a picture/ symbol format, and through voice notes or short video clips. Particular attention was paid to the venue, timings, and catering arrangements. Frequent breaks and opportunities for networking and building community were commonly highlighted as important in feedback. Flexibility around timings and tasks was essential, as some groups finished their tasks early, whilst others struggled to complete their tasks in the allotted time. Additional strategies to help facilitate engagement and recognition of the group included the use of colour coding each group (balloons at the table, all materials produced were colour coded, participants name badges etc). Each group had two skilled facilitators who had extensive experience of working with people with intellectual disabilities and knowledge of EB CD.
Stage: Celebration event Purpose: Share and further develop service pathways and improvement tools	Additional ideas for intervention refinement were collated following the workshop and changes made to the intervention. These were then shared with stakeholders in a written format and feedback provided. Further changes were subsequently made to the intervention. This allowed more specific feedback around different aspects of the

	intervention to be gathered from those with the most relevant experience.
Stage: Design for feasibility testing Purpose: Check existing evidence for proposed solutions, map on to chosen theory and create causal model and fully develop prototypes	Feedback was sought from stakeholders and people with intellectual disabilities regarding the additional materials produced to support intervention delivery. This was gathered through individual and small group discussions to improve accessibility (eliminating the need for literacy skills). Other intervention refinements were also shared with stakeholders in a written format, with feedback received and acted on.
Stage: Feasibility/ pilot and main study Purpose: Implement, refine and test solutions in experimental research study	Initial testing of the intervention is currently occurring in NHS settings using single case experimental design with people with mild to moderate intellectual disabilities and anxiety.
Data and analysis from earlier qualitative and/or quantitative exploration in this context and findings from the broader literature are always available)	We found the use of previous qualitative studies and a systematic review, as well as consultation with the broader literature was invaluable in feeding into all stages of this process.

to ask questions and for clarification. It was made clear to participants that there were no right or wrong answers and that the facilitator was interested in hearing all of their ideas, and especially any concerns or areas of confusion regarding the intervention. The facilitator made sure to provide feedback and positive reinforcement for all contributions from participants and to encourage discussion between participants.

At the start of the group, the three parameters of the intervention set by the research team were outlined and the rationale for these provided. Participants were invited to discuss all aspects of the intervention. A specific aim of the focus group was for participants to understand the three mental imagery components of the intervention, and to discuss how these could be presented to patients. The exercises proposed to teach each mental imagery component were explained and tried out in the focus group, and feedback provided. The first mental imagery component is that of generating helpful mental imagery. This is done through one of two exercises adapted for people with intellectual disability and based on Compassion Focused Therapy. To demonstrate these two exercises, the facilitator read each exercise from a script and encouraged the participants to engage with the exercise in the room. The two exercises were 'Calm Place' and 'Kind Helper' (adapted perfect nurturer exercise; Lee, 2005). The second mental imagery component is that of switching attention from an internal image to external stimuli. This was demonstrated through guiding participants through a grounding exercise (in which they were asked to notice 5 things they could see of a specific colour, and work through the other senses to focus attention in the room). It was also demonstrated through use of multi-sensory objects such as different essential oils to smell, different sensory toys to touch etc. Finally, participants were guided through an exercise to change the properties of an image. This was demonstrated

through viewing a short film clip which demonstrates the technique. Additionally, group discussions concerned the logistics of providing an accessible talking therapy for people with intellectual disabilities, the materials that should be covered within the intervention (e.g., providing psychoeducation around anxiety), and how people could be helped to remember what new skills they had learned in the therapy. These were elicited through the focus group facilitator asking open ended questions following on from comments made by participants, and subsequent spontaneous conversations between group participants.

Each focus group was audio recorded, transcribed, and analysed using Template Analysis (Brooks et al., 2015). In addition to Template Analysis, the transcripts were analysed to identify ‘touchpoints’. Touchpoints are emotionally charged or key moments and have been defined as any crucial moment that makes a difference (good or bad) to someone’s experience of the environment or process (Robert, 2013). Initially 67 potential touchpoints were identified. These were refined to remove duplicate ideas, and to simplify the language used. Discussion amongst the authors and with stakeholders involved in steering the overall project resulted in the touchpoints being reduced to 46 touchpoints.

Stage 2

A second series of five focus groups (three with people with intellectual disabilities and two with stakeholders) were held to consider the identified touchpoints. Each focus group lasted around one hour. Each touchpoint was printed onto a card in large type and placed upon a table in front of the participants. Each focus group was asked to cluster together touchpoints into meaningful groups. To facilitate this process for people with intellectual disabilities, these groups chose to use a pen to underline

any key words in the touchpoint and this helped them to group together touchpoints that referenced similar concepts. Once the touchpoints were clustered together, the group named each cluster with a title that summarised the concepts it contained. Groups then ranked each cluster in terms of its priority for action. Generally, groups chose to move these clusters around the table, physically representing their order of importance.

Following these five focus groups, 33 clusters had been identified and ranked by the groups. Most groups had clustered their touchpoints in similar ways, meaning there was a large amount of overlap between these 33 clusters. The 33 clusters were synthesised by OH and discussed with ML. This resulted in eight themes of synthesised clusters being identified. The five most prevalent clusters were then taken forward to the workshop (Stage 3) to form the topics for small group work.

Stage 3

A one-day workshop was held in an accessible community venue. This was attended by 48 participants, including 16 people with intellectual disabilities. The day consisted of viewing a series of short trigger films made by people with intellectual disabilities who were part of the steering group for the overall project. These films focused on their experience of anxiety, the impact anxiety had on their everyday life, and their thoughts about engaging with the mental imagery intervention. Trigger films are used to generate discussion and to support priority setting around intervention adaptation. For example, a person talking about feeling misunderstood and isolated by anxiety may have led to discussion around the importance of psychoeducation within the intervention, whether having a supported attending therapy sessions could reduce

isolation, or whether additional strategies such as developing social networks should be included in the intervention.

During the workshop, five groups consisting of people with intellectual disabilities and stakeholders explored topics to further refine the intervention. Each group was given a colour as well as a name to help aid recognition for all group members. Paperwork, badges and balloons at each table were similarly colour coordinated to help participants identify their own table and topic. The five most prevalent themes from Stage 2 were taken forward as the topics for this small group work. Each small group spent time completing a task to help answer or address the outstanding issue that required resolution. A list of the small group topics, their aims, and the activities to address these aims is given in Table 3. Each small group completed a task to resolve the outstanding issue, and discussion amongst all member so the group helped to explore alternative amendments, before clarifying the groups decision about how best to resolve the issue. Group discussion was facilitated by two group members who had in depth knowledge of the issue being presented, and of working with people with intellectual disability. Their facilitation ensured all group members understood the task and were able to contribute their ideas to the discussion. Following the two hour long sessions of group work (before and after lunch), each group completed a decision grid that specified ‘What action we have decided should happen?’, ‘Why did we decide this?’, ‘Who will do it?’, ‘By when?’, ‘Any barriers that might get in the way?’, and ‘What will be different when it has been done?’. This helped to detail each recommendation made by the group to further develop the intervention. In addition, each group facilitator fed back the content of the group discussions, to detail what ideas were taken forward by the group as well as those rejected. Each facilitator

Table 3*Details of Small Group Work Completed During the Workshop*

Name of workgroup	The role of supporters	Accessibility and engagement	Understanding anxiety	Measuring anxiety	Mental imagery components
Colour	Green	Pink	Orange	Purple	Blue
Aim	•How can we help people identify the right supporter? •How can we balance confidentiality with sharing information with supporters?	•How to make the intervention as interesting and fun as possible? •How to make the materials as accessible as possible?	•What do people need to know about anxiety before we start the intervention? •How should we help them to know about this?	•How can we help people report how they are feeling every day?	•How to make the mental imagery exercises as accessible as possible? •How to help people practice these skills outside sessions?
Task	Watch role plays illustrating examples of good and bad supporters	Add sticky notes to a visual plan of the intervention to identify areas to improve accessibility and engagement	Review different anxiety psychoeducation materials and decide which should be included in the intervention.	Consider different ways of reporting the person's mood on a daily basis.	Go through mental imagery exercises and give feedback on accessibility. Generate ideas to help practice skills between sessions.
Example of decisions made by the group	To add information about what a good and bad supporter looks like to the client workbook. Include information about what to do if unhappy with their supporter. Therapist to go through this information with them at beginning of therapy	Add multi-sensory items e.g. music, scents to the therapy (if the client enjoys these) to enhance mental imagery and increase engagement. Explore these ideas in session 4 and include in blueprint if helpful.	Provide written information about anxiety at screening	Need flexible options for daily recording. Consider format of recordings (electronic/ paper/app) What support required to set this up?	Record the therapist talking through the calm place/ kind helper exercises so the person can use to practice these in between sessions.

also captured their own reflections on the process which were discussed by the research team.

Capturing Feedback on the EBCD Process

To understand the experiences of those involved with the EBCD process, questionnaires and semi structured interviews were employed. Quantitative questionnaires were administered to all participants (stakeholders and people with intellectual disabilities) at the end of the Stage 1 and Stage 2 focus groups and following the Stage 3 workshop. Items in these questionnaires were taken from Frankena et al.'s (2019) consensus statement on how to conduct inclusive health research, and included items reflecting of personal, professional, research, healthcare, and societal areas. Some longer items were shortened or simplified before being included in the feedback questionnaire. Questionnaires were designed to be quick and simple to complete, and responses were anonymous. Stakeholder participants were asked to endorse any of the 32 items presented to them that reflected their experience of the focus group or workshop. An adapted version was provided for people with intellectual disabilities with 16 items being provided in large text using simple language and with an accompanying image (taken from Easy on the I image bank). Each item was kept to a short sentence (maximum seven words). Respondents could mark yes or no to each item. Yes and no responses were also represented through symbols. Both versions of the questionnaires are available from the authors on request.

Questionnaires were administered by giving a hard copy of the relevant questionnaire to the participant at the end of the focus group or workshop, and ensuring they had a pen or pencil to complete the questionnaire. The response format was explained to the participant, and they were asked if they had any questions. A member

of the research team was available in the room throughout the completion of the questionnaire to answer any questions or clarify any items if necessary.

Semi structured interviews were conducted, transcribed and anonymised by research assistants from outside of the project to encourage honest feedback on the process. Semi structured interview schedules were devised by the research team (based on Fylan et al., 2022) and focused on collecting information about the participants experience of each phase of the project they were involved with, specific processes and techniques within EBCD (such as watching the trigger film, and categorising touchpoints), and interpersonal aspects such as their ability to share thoughts and ideas with other participants. Interviews were conducted with six stakeholders (EBCD01-06) and eight people with intellectual disabilities (EBCD07-EBCD13). They were analysed using Template Analysis by OH. The template was based on Mulvale et al. (2019) and included additional items from Frankena et al. (2019) as well as items arising from the transcripts. Template analysis was chosen as it is a pragmatic and flexible tool allowing particular attention to be paid to material corresponding to the existing consensus statement (which we expected would arise through the interviews) but also allowing flexibility for novel and unexpected areas to be identified.

Results

Having described the process of adapting EBCD to develop an intervention with people with intellectual disabilities and stakeholders, the amendments to the intervention that came from this process will be detailed. Subsequently the experiences of participating in the EBCD process will be explored.

What Were the Intervention Refinements Produced Through EBCD and How Were These Implemented?

A total of 24 discreet refinements were described through the EBCD process (see Table 4).

As well as describing refinements, small groups in Stage 3 provided instructions for implementing these refinements, including a rationale for the amendment, who should make the change and within what time frame this should happen through a detailed decision grid. Any barriers to the change were identified and information provided on what would be different within the intervention once the change had been achieved. Groups completed the task given to them which was designed to facilitate a discussion about how best to resolve the issue being presented. Two skilled facilitators guided the group discussion to ensure that all group members were able to continue and that a range of options were explored. During the group discussion one facilitator made notes regarding the topics and ideas discussed as well as ideas or strategies that were rejected by the group. These were fed back to the research team at the end of the workshop. The use of a structured and detailed decision grid which the group completed together allowed for detail about decision taken to be communicated to the research team and reflect the opinions of all group members, rather than relying on the recall of facilitators.

Proposed changes to the intervention ranged in scale from relatively minor amendments such as checking when people may require a break in a therapy session, to much larger changes, such as devising and including a 'person's workbook' which encompasses a range of worksheets and information about the different intervention sessions.

Table 4*Changes Made to the Intervention Following the EBCD Process*

What we have decided should happen	Why did we decide this?	Who will do it?	By when?	Any barriers that might get in the way?	What will be different when it has been done?
Have a range of prompts to help people develop their mental imagery. These could include physical pictures people could choose from to help them develop their imagery.	To be more person centred	Therapist to discuss with client and supporter in sessions 3 and 4. Could be a homework task after session 3?	OH to add prompt to session materials before study opens for recruitment	Client may not engage with homework task so therapist may need to have some back up options	
Have a recording of the therapist talking through the calm place/ kind helper exercises that the person can use to practice these in between sessions.	To help the client practice new skills and reduce anxiety	Therapist to make recording with client in session 5	Session 5	Client may not have access to device on which to play recording of these exercises. Alternative could be to access online versions that already exist or to use supporter's device.	Client has independent access to accessible materials to practice helpful imagery
To check with the client around their preferred terms for the helpful image exercises. Might rename the calm place as the 'happy place' and the kind helper as a 'kind person'.	To be more accessible and person centred	Client and therapist in session 5. OH to add prompt to therapist manual to check for this	Session 5		More personalised materials
Change visual analogue scale (VAS) to have 3 or 5 options and use faces to indicate how	To be more personalised and accessible	To have different VAS options	Session 6		More personalised materials

someone is feeling (used in attention switching task)		available for use in session 6			
Use sensory cues such as smells or pictures to help people practice using the calm place and kind helper exercises in between sessions.	To help the client practice new skills and reduce anxiety	Client and therapist (and supporter) to discuss in session 4 or 5. OH to add prompt to therapist manual to check for this and to client workbook	Session 4		Help client remember to practice new skills between sessions
Have discussion with client about the role of supporter at beginning of therapy but make time to revisit this throughout therapy sessions. Also revisit how involved the supporter is and if this needs to be changed.	Need to be flexible to make sure the person is appropriately supported	OH to add written easy read information about supporter and their role to client workbook. OH to add prompt to each therapy session to check with client that they are happy with their supporter and how involved this person is.	Before opening recruitment	none	Written record of role of supporter and what client wants from them
To add information about what a good and bad supporter looks like to the client workbook. To include information about what the person can do if they	To empower clients to think about what they want from their supporter	OH to add written information to client workbook	Before opening recruitment	none	Written record of role of supporter and what client wants from them

are not happy with their supporter. Therapist to go through this information with them at beginning of therapy.					
Supporter can be involved with planning and preparing around sessions with client	Help client feel more comfortable with session content	OH to add written information to client workbook for client and supporter to suggest this	Throughout intervention	Supporter or client may not want to do this	Better support for client throughout intervention
Reasonable adjustments. Therapist and supporter to check with client throughout the intervention what reasonable adjustments might be helpful and work together with client to implement these	Make intervention more accessible	OH to add prompt for therapist to check accessibility and reasonable adjustments in each therapy session	Throughout intervention	Client may not know what adjustments are needed or be worried about bringing up difficulties in comprehension	Improved accessibility
A brief (1 session) component to look at understanding anxiety to be included in the intervention.	More detailed information was not thought to be helpful or necessary	OH	Before opening recruitment to study	none	Basic, written information about anxiety provided
Materials about anxiety should be easy read and have pictures. Only simple text. To be included in a client workbook	Client can look at materials in advance and share them with supporter or staff	OH	Before opening recruitment to study	Literacy skills	
Personalise the materials (e.g. only include information about medication if it is particularly relevant for the person)	To be more person centred	Therapist/ supporter/ client throughout intervention	Before opening recruitment to study	Need to check with person and possibly supporter to make sure this is appropriate. May	More personalised/ person centred materials

Have a choice of formats (paper based but also electronic options as well)				need to be changed or adapted over time	
Provide written information about anxiety at screening stage	People would like the information about anxiety before they start the intervention and to be able to go through it with someone they know and trust like a support worker or family member.	Research team	Before opening recruitment to study	none	
Include some information about strategies to help with relaxation at the same time as giving information about anxiety.	People said this would be helpful for them to manage their anxiety	OH	Before opening recruitment to study	none	
At the start of therapy the therapist and client (and maybe supporter) need to have a conversation to make sure the intervention is going to be as accessible as possible. This involves asking the client (and maybe their supporter) to discuss the following with the therapist: • How long are sessions? • How often are sessions? • Where should they take place? • Do they prefer a morning or afternoon session?	Need to make the intervention person centred.	OH to add section to screening session or first therapy session.	Before starting to recruit to intervention	Communication from the service user on what they would like	There will be a document to capture how best to communicate with the client and this can be referred back to in the therapy. This document can be part of the client's workbook.

• Do they need a break in the session and how could they make this known? • What is the persons level of literacy? • How do they prefer to communicate (pictures/ writing/ easy read)? • Who else needs information to be shared with them? (family? Supporter? keyworker?) • Would they prefer individual or group intervention? • Do they need a supporter?					
Add to session 1 – as well as discussing confidentiality and the limits of this, discuss the role of supporter and how much information to share with them and how to do this i.e. with client or not etc. Revisit this throughout the therapy (i.e. add as a session point to each therapy session.	Need to have a clear discussion about boundaries, confidentiality and what information to share. This is especially important in a group setting, but also to think about what to share with supports of other people	OH to add section to screening session or first therapy session. OH to add prompt to revisit this at end of every therapy session	Before starting to recruit to intervention	none	Written prompt to discuss boundaries in the intervention to remind therapists
Provide easy read summary of each session for client in	So people know what is coming up in sessions.	OH to make these materials	before starting to	none	Accessible materials provided to client at

advance. Could be a one side A4 sheet. Could compile these into a workbook for the intervention for the client so they can share materials with others. Some clients might find it overwhelming to have too much information at once so we could add to the workbook week by week if they prefer that.	And so they can share their therapy with others if they want. And to remind them of what they have already covered in sessions. Allows for reinforcement of what has been done. Managing expectations. Helps with practicing		recruit to study		start of therapy. Resource to refer back to on what each session is and why
Add multi-sensory items to the therapy if the client enjoys these. They might include music/ sensory prompts etc to help enhance mental imagery and to increase engagement. Add prompt to session 4 to explore these ideas with clients and revisit in sessions 5, 6 and 7. To include in blueprint if useful for client.	To enhance the vividness of mental imagery and make the therapy more interesting and engaging. Also can use these as cues to practice skills between sessions.	OH to add prompts to discuss in sessions 4,5,6 and 7 and to add to blueprint if appropriate	before starting to recruit to study	If sensory items cannot be identified. If service user isn't calm before explaining plan. If you don't know enough yet	Multi-sensory prompts added to mental imagery intervention sessions Therapy plan Goal setting
Add relaxation exercise at start of each session	To help client relax and feel calm enough to engage with therapy	OH to add a check in at start of each therapy session with option of doing relaxation exercise/ breathing	before starting to recruit to study	none	Clients offered option of relaxation/ breathing to start each session

Offer flexibility around standardised questionnaires – make sure they are as accessible as possible (easy read/ pictures/ large text). Offer breaks when completing them. Could also complete them with supporter if too many to do all at once.	Questionnaires can be long and boring	OH and / or supporter	before starting to recruit to study	none	Questionnaires feel more manageable and can be done at client's own pace
To talk with client and supporter about how they can make the therapy more fun and engaging. Ideas include: • Add in pictures/ colours the client likes • What rewards could they have to help keep them motivated? • Certificates at end of therapy? • Ending with a game	Therapy needs to be more fun!	OH, client and supporter to discuss in screening session or first therapy session. OH to add section to screening session or first therapy session to prompt for this	before starting to recruit to study	none	Therapy will feel more fun and engaging for client
Spend time at start of therapy getting to know client and what their favourite things are eg animals, hobbies, food etc	Therapist needs to build rapport and will give them ideas for helpful imagery	Therapist in session1 and 2 (and throughout intervention)	before starting to recruit to study	none	Build therapeutic relationship
Skills practice/ clarification. How will the client know when to use these mental imagery skills? What will help them remember to do this?	Need to make sure service user understands when to use it	psychologist	Before bulk of therapy/ early sessions		
Need flexible options for daily recording. Will need to establish what will work best for each client before starting therapy.	Need to be person centred	OH to devise worksheet	Before opening recruitment	none	Written document of how best to do daily recordings for this person and why

Need a worksheet for therapist and client (and supporter?) at screening stage to explore how best to do daily recordings. Questions to ask: • Electronic or paper format? • Would they prefer to use an app (such as Daylio)? If so what support do they need to set this up? • Would they prefer to use text or email? • Do they need support to remember to complete a daily measure? Could this be a text reminder (would they like more than 1 reminder a day?) • Do they prefer words/ emojis/ faces/ thumbs up or down/ numbers to represent how they are feeling? • If using paper format what would this look like? And how would they communicate the recordings to the research team?					
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It was reassuring that people with intellectual disabilities, and stakeholders were able to engage with the EBCD process and use the workgroups and decision-making grid to provide a range of feedback and refinements to the interventions. All three mental imagery components presented were retained within the intervention, with various amendments. Decisions included those at a micro level (concerning fine detail of the intervention) as well as overarching ideas, indicating that people were able to hold both multiple aspects of the intervention in mind and provide concrete and specific feedback as to what improvements could be made at each level. Additionally, the feedback provided was extremely helpful. At times the feedback included ideas that had been generated through discussion within the research team and had already been included in the intervention (which was reassuring, indicating that such amendments were endorsed by other stakeholders and service users). Other suggestions for amendments included novel ideas which were then implemented into the intervention before it was tested out within NHS services.

The recommendations from the Stage 3 workshop were largely implemented by the research team. The treatment protocol, therapist's manual and other study documentation were updated to incorporate these refinements, and other new materials were developed (e.g. the person's workbook). All written materials were then circulated to a group of stakeholders for written feedback and further changes to wording, font size, layout etc made to improve accessibility. Individual and small group discussions took place with people with intellectual disabilities to provide feedback on the result of their input at the workshop, and to gain verbal feedback on these additional materials.

What Were the Experiences of Being Involved (Stakeholders, PWID and Researchers) with EBCD (i.e. Was it Acceptable as a Process)?

Results from Questionnaires

Overall results from questionnaires were generally very positive, and feedback for Stage 3 was almost entirely positive.

People with intellectual disability provided overwhelmingly positive feedback on the questionnaires regarding their experiences of the project. They unanimously endorsed that they had been heard within the research, took an active role in the research and that the research was helping to make services accessible and tell others what was important about their health. They described the project as being fun, an opportunity to learn new skills, and to work with other researchers.

Results from the questionnaires completed by stakeholders indicated that people generally enjoyed and engaged with the process. They found that it was meaningful and personally rewarding, as well as contributing to reducing health inequalities. Questionnaires completed by Stakeholders after Focus group 1 and especially focus group 2 had a smaller number of respondents and showed mixed experiences. Understandably, stakeholder participants in focus groups (in which no participants with intellectual disability were present) were less likely to endorse that the experience was inclusive and heard the voices of people with intellectual disability. It seems that Stage 3 was viewed most positively by both groups, where the mixed discussion groups allowed the inclusive nature of the project to be clearly demonstrated.

Table 5*Themes Endorsed by Participants in Semi Structured Interviews*

Participant group	Stakeholder participants						Participants with intellectual disability						
	EBCD01	EBCD02	EBCD03	EBCD04	EBCD05	EBCD06	EBCD07	EBCD08	EBCD09	EBCD10	EBCD11	EBCD12	EBCD13
<u>Working well together</u>													
Developing trust	✓	✓	✓								✓		✓
Really being listened to	✓		✓		✓	✓	✓	✓		✓			✓
Finding voice	✓		✓	✓	✓	✓	✓	✓			✓	✓	
Having a skilful facilitator	✓		✓		✓	✓	✓			✓		✓	
Ensuring the right mix of participants	✓	✓	✓	✓	✓	✓			✓			✓	
Working together	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
Enjoying the research process	✓		✓			✓	✓	✓		✓			✓
Good communication	✓	✓	✓				✓						
<u>Developing research relationships</u>													
Building community	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓
Feeling connected	✓	✓	✓	✓	✓	✓						✓	✓

Collaboration	✓	✓	✓	✓		✓	✓					✓	✓
Sustaining engagement	✓	✓				✓				✓			
Creating a collective vision	✓	✓	✓		✓	✓							
<u>Sharing responsibility for the research</u>													
Sharing power	✓		✓	✓									
Taking on leadership roles in the project	✓		✓	✓		✓				✓			✓
Feeling responsible for the research	✓			✓			✓						✓
Mutual respect	✓	✓								✓			
Research is intellectually challenging				✓		✓						✓	
Intellectual interest in the project	✓	✓	✓		✓	✓	✓		✓			✓	✓
<u>Making a meaningful contribution to the research</u>													
Feeling input is valued	✓	✓	✓	✓	✓	✓			✓				
Contributing to the research	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	

Layering ideas	✓		✓										
Sharing ideas	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
Sharing different perspectives	✓	✓	✓	✓	✓	✓		✓			✓		
Being able to give honest feedback	✓	✓	✓	✓	✓	✓	✓	✓				✓	
Valuing the ethos of codesign	✓	✓	✓		✓	✓	✓	✓	✓	✓		✓	✓
Meetings need to be accessible						✓	✓		✓	✓	✓		✓

Results from Semi Structured Interviews

Template Analysis of the semi structured interviews identified a total of 27 subthemes which were synthesised into four overarching themes (see Table 5). The subthemes endorsed by each participant was decided by OH after careful reading of the transcript.

Theme 1: Working Well Together.

This theme encompassed a number of factors that participants identified as being necessary for the group to work well together. It included each person feeling safe to speak up, and the role of a skilled facilitator in managing discussions. Most participants described having a range of people from different backgrounds and perspectives was helpful to facilitate meaningful discussions. For one participant, the role of the facilitator was key in helping to develop a sense of trust for other participants:

EBCD02: “[It] is about the person whose pulling this all together and creating that sort of feeling of collaboration and and giving people a sense of trust that you know getting involved with this will be the safe space”

Another participant described how, when this skilled facilitation was lacking in an online group, the process felt less safe: “And it would have been better if somebody had facilitated that bit because people were just moving these post-it notes around the screen and they were obviously thinking on a faster level than me. And I was just thinking, ‘Oh my.’” (EBCD06)

Theme 2: Developing Research Relationships.

The second theme described various aspects of building and developing a research community. This included sustaining engagement with participants over the 12 months of the EBCD phase. Over this time, people talked about a deepening of connection and relationship with other co-researchers, which was very much valued, and allowed a collective vision of the research project to crystalise, as this stakeholder described:

EBCD01: “When you're in the meetings, you're listening to other people and their ideas, and even if their idea might be completely different to yours or something you've never heard of before. Nobody kind of interrupted each other or anything else [...] so everybody got to say what they wanted to, and sometimes we might all agree with stuff. Sometimes we wouldn't, but we would come to because there was something on here about bringing everything together. In the collective voice.”

This process was described by a person with intellectual disabilities:

EBCD10: “Yes, I listen to them first and then they listen to me and [we] agreed on things.”

Theme 3: Sharing Responsibility for the Research.

Within this theme, aspects of sharing responsibility for the research were explored. Interestingly several people (two stakeholders and two people with intellectual disabilities) described the weight of responsibility they felt to get things right for the research project, and to make sure they were putting in sufficient work and effort into the process. This was interesting for the research team to hear and prompted reflections on the potential burdens of involvement in the project. However, when

considered alongside the endorsement by six participants of the subtheme ‘taking on a leadership role in the research’, it appeared that people felt able to take an active co-research role in the project, which is a key aim of EBCD. Therefore, it may be that this feeling of responsibility is a necessary aspect of true co-design and thus reflects the level of engagement and investment people felt towards the project. One person with intellectual disabilities described her feelings about the workshop event:

EBCD13: “It was a good day. It was a really good day...Seeing lots of people. We were responsible for it in fact.

Theme 4: Making a Meaningful Contribution to the Research.

This fourth theme described how people felt their input was meaningful and valuable to the research. As part of this, eight people emphasised the need to give honest feedback to the research team, and to feel comfortable doing this. People described their input into concrete tasks such as producing the trigger films as being valued:

Interviewer: “How did you feel about your video being put on on that presentation?”

EBCD10: “I was happy. They want to know what we're saying and that helped them.”

However, there were occasions when the input from people could not be acted on, and this led to some difficulties for one person:

EBCD12: “[researcher] asked us what we would like to do at the workshop and some of it we didn't do because we didn't play bingo and we didn't have music.”

Interviewer: “How did that make you feel?”

EBCD12: “Upset”

Overall, there was a strong sense of support for the underlying principles of co-design, and a sense that having people with intellectual disabilities actively involved in the research was a valuable personal experience and made a genuine difference to the intervention.

EBCD08: “To open up. Umm yeah, it's good and. And get our feelings across.

Because, like, we need more people with like learning disabilities. Like all all of like people from from all over, like, from all over the country”

Discussion

How EBCD was Adapted to Co-Design an Intervention for People with Intellectual Disabilities and Stakeholders

Various adaptations were made to the EBCD process, including generic adaptations to make information more accessible for people with intellectual disabilities. Additionally, each stage of the EBCD process was also considered and adapted to enhance engagement. Whilst many adaptations were required, the underlying structure of EBCD remained intact. Both people with intellectual disabilities and stakeholders could engage with the process of EBCD to develop and refine a psychological intervention. They made meaningful and useful contributions to the intervention, including providing a range of concrete and specific ideas for developing and improving the intervention. Generally, participants found the process to be accessible and enjoyed taking part in it. They were able to provide a range of feedback

about their experiences, and as such provide valuable insights for others who may wish to use this flexible approach to intervention development.

Refinements Produced Through the EBCD Process.

Given that the process of EBCD incorporates multiple, iterative stages, it may have been expected that most of the changes or adaptations the intervention required would have been made and implemented before the final Stage 3 workshop. However, the workshop produced a large number of detailed suggestions for intervention refinement. These focused on both the micro level and broader, overarching principles of the intervention. The use of the decision grid template ensured that feedback was specific and actionable which was helpful to ensure changes could be implemented accurately. The research team were somewhat surprised by the volume of amendments, and as some suggestions required large, new materials to be produced, a considerable amount of work was required to implement these changes in a timely way before the intervention began testing in an NHS setting.

One issue that arose in this project and is described by Fylan et al. (2021), is that while EBCD allows participants to be creative in the solutions they suggest, the research process requires that these solutions are screened and validated, meaning not all suggestions can be adopted. Similarly, one participant was upset that their suggestions for specific food items and the incorporation of games were not able to be included (although several of their other suggestions were incorporated).

Understanding the Experiences of Participating in EBCD

The response rates were very variable for the feedback forms, with high return rates for in person meetings, and very low rates when meetings were held online (i.e.

Stakeholder Stage 2), possible due to difficulties in completing online forms. Online sessions were experienced as having pros and cons for stakeholders. They found that skilled facilitation of group work was less successful in online platforms, although the lack of travel meant attending such meetings was easier to manage with competing work demands.

Relatively few men took part in the project. This may be due to the overrepresentation of women in caring and support worker roles, reflecting the persistent cultural norm that care work should be undertaken by women. Similarly, the lack of men with intellectual disability taking part in focus groups or other discussions may be due to a discomfort in discussing mental health issues including anxiety.

Questionnaire feedback was most positive for Stage 3 which may reflect the increased scope of the workshop (e.g. this larger event provided more networking opportunities), as well as understanding how different stages of the process cumulated in the workshop event. This sense of information flowing from one stage to the next may have helped participants understand the overarching process of EBCD and been reflected in more positive evaluations.

Research assistants who were naive to the project and participants (but who had experience of working with people with intellectual disabilities) were employed to conduct semi structured interviews. Despite this, interviews were overwhelmingly positive. This contrasts with some of the quantitative feedback from stakeholders (especially regarding focus groups 1 and 2) which reflected more ambivalent experiences of the process. However, the small number of respondents providing feedback from the stakeholder focus group 2 was due to the meeting being held online,

and feedback was therefore skewed by one participant who found the meeting to be difficult to engage with. Their experience was explored in an interview and fed through in the qualitative results.

Of the four themes identified in the semi structured interviews, the first two themes focused on the interpersonal relationships that were needed for individuals to feel safe to participate meaningfully in the research process, and building the research community required to complete the project. The other themes focused on the individual responsibility a person experienced for ensuring the project was completed in a timely way and to a high standard. This was experienced by stakeholders and people with intellectual disability, reflecting the investment they felt in the project. The final theme was around feeling that their input was valuable and had been valued by others. The role of participants at the centre of the EBCD design allowed them to see clearly how invaluable their contribution was.

Challenges and Merits of Using EBCD.

The additional burdens and barriers to using co-design with people with intellectual disabilities has been well documented (e.g. Bishop et al., 2024; Hewitt et al., 2023). Within this project, additional adaptations needed to be made to ensure that people were able to access meetings, such as holding these at day centres. The Stage 3 workshop event was noisier and more crowded than would have been preferable, due to several participants not providing an RSVP and arriving unexpectedly on the day.

When engaging participants in the EBCD process, materials are presented to elicit discussion and feedback. When presenting the development of the intervention in this project, three parameters were discussed and agreed by the research team. This

meant that there were some constraints regarding the direction the intervention could be taken through the EBCD process. Although these parameters were kept to a minimum and were felt necessary to ensure that an evidence-based intervention with clear theory of change could be produced, a criticism of the current study may be that providing examples of just three mental imagery components was overly restrictive. Presenting a wider range of potential components may have resulted in different components being selected for the intervention. Whilst the parameter of making the intervention accessible for people with mild to moderate intellectual disabilities was presented by the researcher team, participants in the EBCD process were keen to think about what aspects could be made accessible to people with more severe intellectual disabilities, and in what ways images such as videos and photos could be incorporated into anxiety interventions for this client group.

EBCD has a relatively rigid structure, may be found to lack flexibility (Green et al., 2020). However, we found the clear delineation of the stages of EBCD to be an advantage when working with people with complex and additional needs. The distinct stages of the methodology allowed researchers and those engaging in EBCD to understand clearly each stage of the project, and how each fed into subsequent phases. Thus, we felt that rather than hindering engagement through a lack of flexibility, this rigidity and structure made the methodology more accessible to people with intellectual disabilities.

Epistemic injustice refers to injustice relating to knowledge. It results in people being systematically discredited or neglected and includes silencing and exclusion. Through using the structured and robust framework of EBCD, we ensured that people

with limited communication skills were heard from, and their opinions were able to make real change. Qualitative feedback emphasised the sense from people with intellectual disabilities and stakeholders that everyone was genuinely engaged with the project and felt able to make a meaningful contribution. Eleven of the 13 people interviewed expressed that they valued and endorsed the underlying ethos of co-design, that of sharing power and responsibility for research with people with intellectual disabilities and other stakeholders, and that taking part in the project was in line with this ethos.

Recommendations for Future Studies

The research team found it helpful to use frameworks or templates within the existing literature to guide parts of the EBCD process. EBCD is flexible and can be easily adapted, and we found that the same was true for how we used different frameworks. Consulting examples of how EBCD has been creatively used in other field such as that of child mental health (e.g. Williamson et al., 2021) was helpful. Receiving expert supervision from those with experience of using EBCD in different patient groups and for other purposes was invaluable and provided confidence to implement and adapt EBCD in creative ways to enhance its accessibility. Making connections with other researchers and clinicians using EBCD was also extremely helpful and allowed for the sharing of ideas and resources. Using specific tools such as GRIPP2 (Staniszewska et al., 2017) ensured phases of the project such as the write up, are conducted in accordance with good practice guidance.

Whilst not all participants will be able to take part in every stage of the EBCD process, we found that it was helpful to have a core group of participants who attended all three stages, as this allowed them to develop a wider perspective and deeper

understanding of the process. EBCD is a large and complex process with multiple iterative rounds of feedback and refinements to incorporate. It requires good organisation and a proactive stance. Participants that are involved in only one stage of the project may require additional information and support to ensure they have sufficient context and understanding of the overall project.

Conclusions

The process of using EBCD provides a helpful framework for a complex, collaborative process. EBCD can be helpfully adapted to form part of designing complex interventions, and this process can be accessible and meaningful for people with intellectual disabilities.

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Chapter 6

Initial Testing of a Novel, Mental Imagery-Based Anxiety Intervention for People with Mild to Moderate Intellectual Disabilities Using a Single Case Experimental Design

Hewitt, O.M., Thompson, P.A., Steel, C. & Langdon, P.E. Initial testing of a novel, mental imagery-based anxiety intervention for people with mild to moderate intellectual disabilities using a single case experimental design. This manuscript is currently under peer review with the Journal of Applied Research in Intellectual Disabilities (JARID) submitted 16 July 2025.

Abstract

Background: People with intellectual disabilities experience higher anxiety rates and barriers accessing effective interventions. This study conducted initial testing and refinement of Co-MAID, a novel mental imagery-based anxiety intervention co-designed with people with mild to moderate intellectual disabilities.

Methods: Six participants receiving 9-12 individual sessions using non-concurrent multiple baseline design. Sessions focused on positive imagery generation, attention shifting, and image property modification. Acceptability was assessed through interviews and adherence measures.

Results: Five participants completed the intervention with 92.6% session attendance. Template analysis revealed positive experiences with improved mood and reduced anxiety. Three participants (50%) demonstrated reliable change on the primary anxiety measure, meeting clinically significant change criteria.

Conclusions: Co-MAID demonstrated good acceptability with some preliminary evidence of anxiety reduction in people with mild to moderate intellectual disability. Further research with larger samples and controlled designs will establish the feasibility of a randomised control trial leading to a Phase III trial.

Lay Summary

- Researchers developed and tested Co-MAID, a new therapy that uses mental imagery to help people with mild to moderate intellectual disabilities manage their anxiety. The therapy was designed together with people who have intellectual disabilities to make sure it worked for them.

- The study involved six people who attended 9 individual therapy sessions with excellent attendance rates (93%). Half of the participants showed meaningful improvements in their anxiety levels, and most participants reported feeling better after the sessions.
- This research is important because people with intellectual disabilities often experience higher levels of anxiety but have fewer treatment options available to them. Co-MAID offers a potentially accessible and effective way to help this population manage anxiety using techniques specifically adapted for their needs.
- This study provides promising early evidence that mental imagery-based interventions can work for people with intellectual disabilities. The positive results suggest this approach deserves further investigation through larger, more comprehensive clinical trials to see if it could become a widely available treatment option

Keywords

Intellectual disability, anxiety, mental imagery, co-design, single case experimental design

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Conflict of Interest Statement

There are no conflicts of interest to declare.

Data Accessibility Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

CRediT Statement

O.H.: Conceptualization, Methodology, Formal analysis, Investigation, Writing - Original Draft, Funding acquisition

P.A.T.: Methodology, Formal analysis, Writing - Review & Editing

C.S.: Conceptualization, Writing - Review & Editing, Funding acquisition, Supervision

P.E.L.: Conceptualization, Methodology, Formal analysis, Writing - Review & Editing, Conceptualization, Supervision, Funding acquisition

Introduction

Anxiety in People with Intellectual Disabilities

Anxiety disorders are common in people with intellectual disabilities, with prevalence rates being between 4-17% (Reid et al., 2011). As with others, people with intellectual disabilities experience various anxiety disorders (e.g. phobias, generalised anxiety disorder etc). Anxiety disorders are distressing, limit daily functioning and quality of life and contribute to poor physical health (e.g. Snoeijen-Schouwenaars et al., 2019; Carmeli et al., 2009; Sareen et al., 2006). Without treatment they generally persist (Dube et al., 2024), highlighting the need for effective and accessible interventions for people with intellectual disabilities.

Cognitive-Behavioural Therapy for People with Intellectual Disabilities

Whilst people with intellectual disabilities experience higher rates of mental health problems than the general population, they are also thought to be less able to use cognitive techniques in addressing their anxiety. Cognitive Behavioural Therapy (CBT) is considered the gold standard intervention for many mental health conditions in the general population, including anxiety disorders (e.g. Stefan et al., 2019; National Institute for Health and Care Excellence, 2020), and has been adapted for this clinical group. A systematic review of nine studies (Fynn et al., 2023) found that while all studies demonstrated some improvement in symptoms of anxiety in people with mild intellectual disabilities following CBT, significant methodological flaws limit the conclusions that can be drawn regarding the effectiveness of CBT for individuals with intellectual disability. In addition, engaging with metacognitive techniques such as cognitive restructuring and thought replacement remain challenging for this population, possibly due to cognitive inflexibility associated with intellectual disability (Rostambeygi

et al., 2021). Studies looking at how to adapt and facilitate these cognitive techniques identify that significant effort is needed in terms of time, rehearsal and modelling, to help those with intellectual disabilities to identify and change their cognition, and that even with such adaptations, there remain significant barriers for many people with intellectual disabilities when engaging with these skills (Roberts & Kwan, 2018).

Mental Imagery

Mental images are representations of sensory information without a direct external stimulus (Pearson et al, 2015). They occur across sensory modalities (“seeing with the mind’s eye” or “hearing with the mind’s ear” etc; Kosslyn et al., 2006), can be fleeting or protracted, and positive, neutral or negative in content.

Whilst mental imagery has a clear role in the development and maintenance of various psychological disorders (Hackmann et al., 2011), psychological interventions largely target unhelpful thoughts using language. However, mental imagery elicits emotions more easily and intensely than verbal thoughts through several mechanisms (Pearson, 2015; Holmes & Matthews, 2010), which suggests various ways of using mental imagery in psychological interventions.

Mental imagery forms an integral part of psychological interventions for mental health problems, including anxiety, in mainstream services, with a robust evidence base (Holmes et al., 2015). Mental imagery-based interventions to reduce psychological distress focus upon increasing the quantity and quality of positive imagery, shifting attention away from distressing imagery, and the use of various metacognitive techniques, such as cognitive restructuring, which includes changing the properties of mental images to demonstrate control over the content and form of imagery. Mental

imagery interventions have been successfully adapted for other populations such as children and adolescents (Pile et al., 2021; Schwarz et al., 2020). However, manipulating mental imagery has never been developed as an intervention for people with intellectual disabilities, despite its potential advantages which include being effective, quick, and posing less of a cognitive burden than verbal-based CBT interventions (Blackwell, 2019).

Developing a Co-Designed Mental Imagery Anxiety Intervention for People with Mild to Moderate Intellectual Disabilities (Co-MAID)

Initially, a systematic review of 41 studies was undertaken to establish that people with intellectual disabilities experience mental imagery similar to people without intellectual disabilities (Hewitt et al., 2022). There was evidence to indicate that people with intellectual disabilities experienced rich and vivid mental imagery which they can generate and transform (essential for engaging in mental imagery interventions). As expected, additional prompting and support was needed to elicit mental imagery. This review established that mental imagery interventions had the potential to be accessible for this population. We then explored the phenomenology of mental imagery in people with intellectual disabilities including their ability to control and manipulate mental images, which further supported the acceptability and potential benefit of mental imagery interventions in the population (Hewitt et al., 2023).

Whilst co-production is best practice to ensure accessibility and acceptability for specific clinical populations, it has rarely been used with people with intellectual disability. Co-MAID is a manualised mental imagery anxiety intervention that was co-developed with people with intellectual disabilities who had various additional mental and physical health difficulties (including cerebral palsy, anxiety, epilepsy and autism)

and other stakeholders, using a rigorous and iterative methodology, Experience-Based Co-Design (Hewitt et al., 2025).

Co-MAID comprises 9-12 individual sessions, including rapport building, formulation, psychoeducation, three mental imagery components (generating positive imagery, shifting attention away from distressing imagery, and changing the properties of an image), and strategies to help participants retain, practice and generalise skills between sessions, and post-intervention. A workbook for people with intellectual disabilities, therapist manual, treatment protocol, and intervention logic model have all been developed. Co-MAID encourages involving a supporter in the intervention to assist with generalising skills and practising imagery techniques post-intervention. A supporter can be a family member or paid support worker, and involvement may include attending therapy sessions and helping with homework tasks. Whilst having a supporter may facilitate engagement, it is not mandatory, as it may not be appropriate or available to all participants.

Aims

The aim of this study was to model the Co-MAID intervention in an NHS setting using Single case Experimental Design (SCED). The primary aim was to investigate intervention acceptability. A secondary aim was to capture data using daily mood recordings and standardised anxiety measures and to examine change pre- and post-intervention.

Method

Design

A non-concurrent multiple baseline (A_1BA_2) case series design was used. A_1 was the multiple baseline phase. Participants were randomly allocated to either a two-, three-, or four-week baseline condition. B was the intervention phase (9-12 sessions of Co-MAID), and A_2 was the corresponding two-, three-, or four-week follow-up period. After the initial three participants were recruited and completed the intervention, the intervention and research methods were refined based upon feedback. Refining the intervention was based on the FRAME expanded framework (Wiltsey Stirman et al., 2019) for reporting adaptations and modification to evidence-based interventions. This allowed intervention refinements to be made and documented in a systematic way with clear evidence trail for each change.

Acceptability was determined using semi structured qualitative interviews conducted with participants and supporters 2 weeks after intervention completion. In addition, brief feedback was obtained from participants at the end of each intervention session (see Figure 1). Participants were invited to complete standardised measures both pre- and post-intervention of anxiety, psychological wellbeing and distress, and vividness and control of mental imagery. Participants were also asked to provide daily mood ratings.

A favourable ethical opinion was obtained from the West of Scotland Research Ethics Service Committee (REF: 24/WS/0022) along with Health Research Authority (HRA) approval. The protocol was registered (ISRCTN70980810). This study is reported in line with the Single-Case Reporting guideline In BEhavioural interventions (SCRIBE) (Tate et al., 2016).

Figure 1

Qualitative Session by Session Feedback Form

Qualitative session by session feedback

Participant number:

Intervention session number:

Name of Therapist:

Date:

We want to know what you think about our sessions together.

How did you find the session today?

good 	all right 	bad 

Open ended questions:

- 'What did you like most about our time together today?'
- 'What did you not like about the session today?'
- 'What would you like to change about our sessions?'
- 'Is there anything else you would like to tell me?'

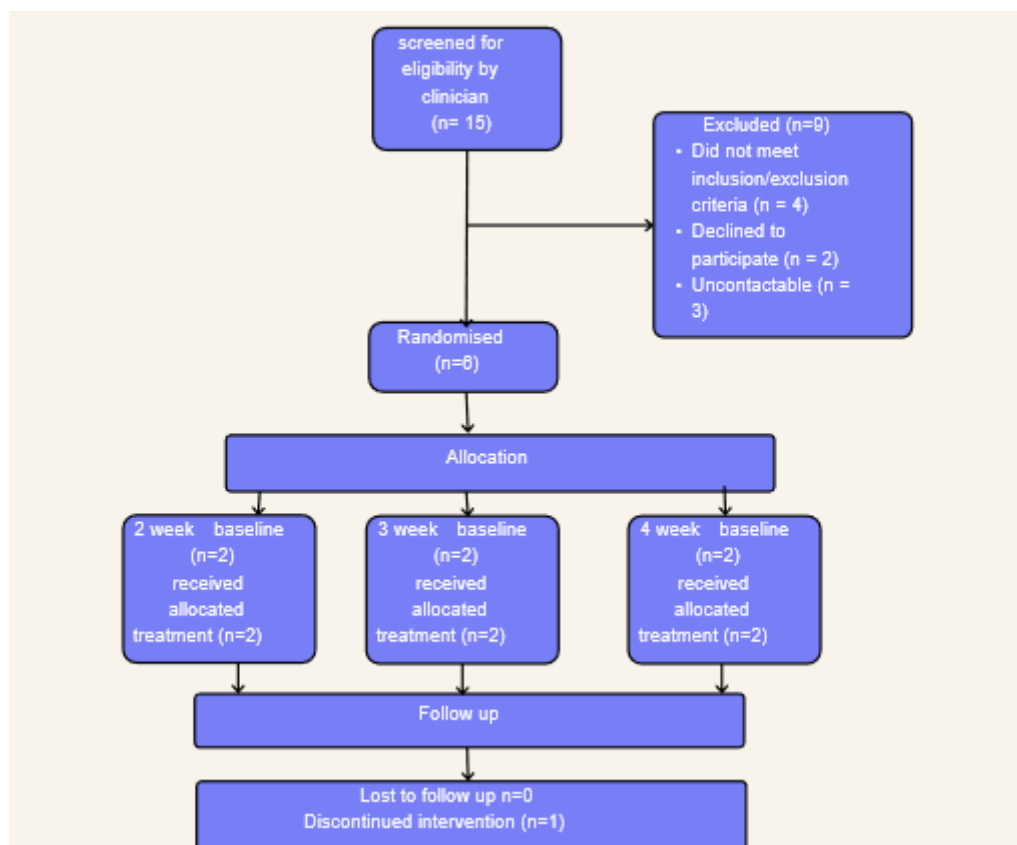
Participants

Inclusion criteria were: (1) Diagnosis of mild or moderate intellectual/ learning disabilities confirmed through case note review or at screening, (2) Aged 18 years or older, (3) Existing diagnosis of an anxiety disorder confirmed at screening (score of 13 or over on GAS-ID) and (4) Capacity to provide informed consent.

Exclusion criteria were (1) Currently receiving another psychological therapy for a mental health problem, (2) Presenting with mental health symptoms of a disorder other than anxiety which were judged likely to interfere with their ability to successful

Figure 2:

Overview of Recruitment and Participation



participate in the intervention by the study team (e.g., hallucinations and delusions or suicidality).

Figure 2 details recruitment and participation. Six participants were recruited from 15 patients screened for participation. Reasons for not participating were: not meeting the inclusion/exclusion criteria ($n = 4$), declining to participate ($n = 2$) and being uncontactable by the researcher ($n = 3$). From the six recruited participants, one discontinued the intervention due to an increase in physical health issues.

Six participants with intellectual disability were recruited through UK learning disability services in one NHS Trust. Five supporters were also recruited. Demographic information for each participant and supporter is provided in Table 1.

Measures

Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID)

The Glasgow Anxiety Scale GAS-ID (Mindham & Espie, 2003) is 27-item self-rating scale measuring symptoms of anxiety in people with intellectual disability. Responses are provided on a 3-point Likert scale of 'no, sometimes' or 'a lot'. Total scores range from 0 to 45, with a higher score indicating higher anxiety. Scores of 13 or over indicate an anxiety disorder. The GAS-ID has good test-retest reliability, internal consistency, and concurrent validity (Mindham & Espie, 2003). This was used as the primary outcome measure.

Adapted Patient Health Questionnaire (PHQ-9)

The PHQ-9 is 9-item questionnaire used to assess the severity of symptoms of depression over the past 2 weeks (Kroenke et al., 2011) in the general population. This has been adapted for use in people with intellectual disabilities (Jenkins et al., 2025), showing good reliability and validity. It consists of 9 items, and responses are provided

on a 4-point Likert scale ranging from 'no days' to 'nearly every day'. Each item is presented in easier read format (large text, visual representation of Likert scale accompanies each item) and picture illustrating the meaning of that item.

Table 1*Demographic Information for Participants and Supporters*

	Age	Reason for referral	Ethnicity	Comorbid conditions	Gender	Level of intellectual disability	Accommodation	Relationship to person with ID	Daytime activities
PPT01	36	anxiety	White British	Fragile X autism	male	moderate	Family home		Attends day services with support
SUP01	69		White British		female			mother	
PPT02	60	anxiety	White British	diabetes	male	mild	Sheltered housing		Attends some community events e.g. Church
SUP02 no supporter available									
PPT03	71	Health anxiety	White British	diabetes enlarged prostate, bladder stones, hypertension,	male	mild	Supported living single occupancy flat		Attends some community events e.g. meeting friends
SUP03	50		White British	Diabetes	female			Paid support worker	
PPT04	33	Health anxiety	White British	Irritable Bowel Syndrome	male	mild	Supported living single occupancy flat		Part time work
SUP04	42		White British		female			Paid support worker	

PPT05	39	Mixed anxiety and depression	White British	Paranoia/ delusions	male	mild	Shared lives scheme		
SUP05	48		White British		female			Shared lives carer	
PPT07	41	Mixed anxiety and depression	White British	Cardiac issues	male	mild	Supported living in group home		none
SUP07	56		White British		female			Paid support worker	

Adapted Generalized Anxiety Disorder (GAD-7)

Generalized Anxiety Disorder (GAD-7) (Spitzer et al., 2006) is a seven-item questionnaire designed to assess levels of generalized anxiety in the general population. It has good levels of validity and reliability and can be used as a self-report or interview administered tool. An adapted version of the GAD-7 has been developed for use with people with intellectual disability (Jenkins et al., 2025) and shows good reliability and validity in this population. responses are provided on a 4-point Likert scale ranging from 'no days' to 'nearly every day'. Each item is presented in easier read format (large text, visual representation of Likert scale accompanies each item) and picture illustrating the meaning of that item.

Psychological Therapies Outcome Scales – Intellectual Disabilities (PTOS-ID)

The Psychological Therapies Outcome Scales – Intellectual Disabilities (PTOS-ID; Vlissides et al., 2017) is a psychometrically robust, three-factor therapy outcome measure designed for use people with intellectual disabilities. It measures overall positive psychological wellbeing and psychological distress (comprising two factors 'anger and mood' and 'anxiety'). Higher scores on the positive wellbeing index indicate higher levels of wellbeing and vice versa on the psychological distress index.

Vividness of Visual Imagery Questionnaire (VVIQ)

The Vividness of Visual Imagery Questionnaire (Marks, 1973) consists of 16 items in four groups of 4 items. Participants consider four different mental images prompted by the interviewer and assess the vividness of aspects of this image on a 5-point Likert scale. To improve accessibility of this measure, the wording used to describe the task was simplified and the interviewer was able to provide additional scaffolding and prompts for participants when completing this measure.

Mental Imagery Questionnaire for People with Intellectual Disability (MIQ-ID)

The Mental Imagery Questionnaire for People with intellectual disability (MIQ-ID) (Hewitt et al, manuscript in preparation) is an eight-item questionnaire, with responses of 'yes', 'sometimes' and 'no' provided on a 3-point Likert scale. It has been adapted from two subscales of the Negative Mental Imagery Questionnaire (MIQ-N; Oaie et al., 2024), concerning realness and controllability of mental imagery. Psychometric testing of this measure is being conducted.

Standardised outcome measures (GAS-ID, PHQ-9, GAD-7, PTOS and either VVIQ or MIQ-ID) were administered at baseline, mid intervention, end of intervention and at 2 week follow up.

Daily Mood Recordings

Daily records of mood on a Likert scale of 1-5 (with corresponding qualitative descriptors) were completed either electronically through the Daylio app or a pen and paper version of these rating scales. For participants using the app, weekly summary reports of daily scores could be emailed to the research team. The Daylio app allows for a daily prompt to be sent to participants to remind them to complete their recording for that day. Four participants recorded their mood independently, and two with assistance from their supporter. Four participants recorded their daily mood through the Daylio app and two used a paper and pen version.

Safety

Safety was evaluated by monitoring and analysing adverse events to determine their severity, expectancy, and relationship to study procedures (Grant et al., 2018).

Intervention

The Co-MAID intervention was delivered to participants by one therapist (OH) via a participant workbook and therapist manual to enhance procedural fidelity.

Intervention sessions for 5 participants were delivered at their home address, with PPT05 receiving the intervention at their local NHS mental health clinic. Aspects of Compassion Focused Therapy are incorporated in the intervention and include developing self-soothing strategies such as grounding and breathing exercises at the start of each therapy session. The main target of the intervention is to develop mental imagery skills, such as generating positive images, and to practice changing aspects of an image to develop metacognitive skills. Examples of changing aspects of an image included perceptual changes (e.g., changing the colours, light, size of the image), behavioural changes (e.g., changing what they did) or relational (e.g., adding someone else into the image). Table 2 summarises the focus of each intervention session.

Table 2

Summary of Content for Intervention Sessions

Baseline assessment	Complete pre-intervention measures and confirm informed consent. - Discuss role of supporter, any limits the participant wishes to put on their involvement, and who might be best placed to support. - Opportunity to build rapport and answer any questions. - Explain therapist's role and that of research assistants. - Introduction to the intervention.
Intervention session 1	Understand the development and presentation of anxiety for the participant. - Learn about anxiety and how this is experienced in our bodies. Understand that anxiety is a feeling and that one of the things that maintains anxiety is the thoughts we have. Thoughts can be verbal or visual.

	- Collaboratively develop formulation about the development and maintenance of anxiety, with emphasis on role of mental imagery as maintaining factor - Focus on rapport building.
Intervention session 2	Psychoeducation about anxiety and mental imagery - Learn about mental imagery. Discuss verbal thoughts vs mental imagery in relation to emotions. - Use examples to explain the power of mental images vs real situations. This could include participants hearing real music vs imagining hearing music. - Learn that having control over our images can reduce the distress caused by the images. - Using positive images to evoke happy and safe feelings.
Intervention session 3	Understanding and practicing mental imagery - Purpose is to help participant understand what we mean by a mental image and to practice their mental imagery skills in terms of generating and manipulating mental images across different sensory modalities. - To continue to explore how mental imagery manipulation can impact on how they feel in their body and their mood. - Identifying an image to work with. To collaboratively explore person's ability to generate mental image and get a full description of the image
Intervention session 4	Mental imagery technique: Generating positive image exercises. - Use the calm place and kind helper exercises. - Agree on the rationale for using positive imagery – could be to increase feelings of calm. - Link the image to a cue e.g. associate image with a smell to help recall. - Audio record the exercise so client can listen back later. - Make a plan about how the images will be practiced in everyday life - / when / to what extent the supporter can be involved with this process between sessions.
Intervention session 5	Mental Imagery technique: Attention switching exercise. - Participant switches focus of attention from internal image to outside world. - Bring to mind a mildly troubling image. What can you see/ smell/ hear/ taste etc? - Check what emotions this provokes and how strong they are (can use visual analogue scale here to help with this) - Shift the participant's focus. Can be done using objects in the room or though looking at a range of additional objects provided by the therapist. Do this for 1 minute - Now bring the focus back to yourself. How do you feel now? What has happened to [emotion]. How strong is it on scale of 1-10? - Identify any ways in which the image and associated emotions have changed. Can ask the participant how or why they think these changes have come about.
Intervention session 6	Mental imagery technique: Changing the properties of an image.

	- Explain rationale for this exercise using clip from Harry Potter and the Prisoner of Azkaban film. - Purpose of exercise is to change the properties of the image. This allows the participant to gain control over the image and to understand that images can be changed and are not reflections of reality per se. - To identify an image to work with. To help the participant identify the emotion it elicits and how strongly this is experienced. - Examples of imagery manipulation techniques include imagining changing the colour of the image or imagining popping the image like a balloon. - To support the participant to experiment with changing different properties of the image. - To revisit the image and identify the emotion it elicits and how strongly this is experienced. - To explore what the participant has learnt from this exercise/ what it means in terms of the reality and controllability of mental imagery
Intervention session 7	Develop Blueprint (possible joint session with supporter) - To work with participant to develop an accessible summary of the work completed. - What did you learn in our sessions together? - How will you practice these new skills? - What will you do to remember to be kind to yourself in the future? - If you were feeling anxious or having tricky images, what would you want to remind yourself of/ say to yourself? - If you were giving advice to someone who also had anxious pictures, like you, what would you say to them to help them feel things were more manageable?
Intervention session 8	Review blueprint, complete post intervention outcome measures (possible joint session with supporter) - To recap blueprint and share with supporter. - To reflect on the work undertaken and how this can be continued/ maintained. - To understand what the participant found to be the most powerful/ helpful mental imagery strategies. - To discuss plan for the future e.g. accessing additional psychological support

Procedure

Participants were recruited through the Psychology service for people with a learning disability in NHS services. Service waiting lists and new referrals were screened for eligibility by clinicians, and those eligible approached by clinicians.

All therapy sessions were completed by OH. Additional research procedures such as gaining informed consent and conducting parts of process evaluation were conducted by a research nurse from the Trust R and D department.

At initial assessment participants completed the GAS-ID, PHQ-9, GAD-7, PTOS and either VVIQ or MIQ-ID. Participants were then randomised into baseline times of varying length which was decided by a computer programme (<https://www.randomizer.org/>) PPT03 and PPT07 were allocated to a 2 week baseline, PPT01 and PPT02 to a three week baseline and PPT04 and PPT05 to a four week baseline. Participants completed the daily mood recordings from assessment until the end of their follow up period (2, 3 or 4 weeks after their final intervention session). No blinding or masking was used. Brief session by session feedback was obtained for each participant, who rated the session 'good', 'OK' or bad' and provided brief feedback on helpful and unhelpful aspects of the therapy session.

Semi structured qualitative interviews were conducted with participants and their supporter at 2 week follow up, by a research nurse who had not been involved in delivering the intervention.

Analysis

Semi structured qualitative interviews with participants (n=5) and supporters (n=3) were conducted at 2 week follow up. Data was analysed using Template Analysis (Brooks et al, 2015). The following steps were undertaken:

1. OH became familiar with the data through repeated reading of transcripts and listening to recordings of the interviews

2. Preliminary coding of the data was conducted. A priori themes were identified in advance through consultation with the literature and discussion within the research teams as likely to be helpful and relevant to the analysis. These were tentative themes which could be removed or redefined if not useful to the analysis.
3. Emerging themes were organised into meaningful clusters, with relationships between groupings being defined
4. An initial coding template was developed on the basis of two participants and one supporter interviews.
5. The initial template was applied to the remaining transcripts and modified to accommodate additional themes

Mood, anxiety symptoms, psychological wellbeing, psychological distress, and mental imagery were evaluated through inspection of descriptive data. Measures of daily mood recordings were entered and graphed using Microsoft Excel. Monitoring phases were separated into baseline (all recordings prior to first intervention session), Intervention (up to the day of last intervention session) and follow up (all recording subsequent to last intervention session). Visual analysis was conducted looking for change in central tendency, trend, or variability, in accordance with visual analysis guidelines (Kazdin, 2011). Statistical analysis of daily mood ratings was conducted using TAU-BC (baseline corrected TAU) calculated to compare each condition (baseline, intervention, follow up) for each participant through a single-case effect size calculator (Pustejovsky et al., 2024). TAU-BC assesses for the presence of monotonic trend in baseline and corrects it, if needed (Tarlow, 2017). Three comparisons were conducted: baseline vs therapy (to control for the effects of time and monitoring); therapy vs follow-

up; and finally baseline and therapy were also combined and compared to follow-up to comprehensively evaluate post-therapy effects compared to the preceding phases. Reliable (RCI) and clinically significant change (CSC; Jacobson & Truax, 1991) were calculated using the Leeds Reliable Change Index Calculator for a single case (Morley & Dowzer, 2014) for the GAS-ID. RCI & CSC were calculated using clinical and non-clinical sample means and standard deviations from previous research (Mindham & Espie, 2003). CSC was calculated using a cut off score of 13.

Results

Adaptations to Intervention

A total of 34 intervention adaptations were collated from feedback from participants, their supporters, the therapist delivering the intervention, NHS service manager, and academic supervisors. Eleven proposed amendments were declined, and the remaining 23 were implemented. The most significant change made was to replace the VVIQ with the MIQ-ID. This was made as participants found the VVIQ burdensome and repetitive. The MIQ-ID has been devised to target pertinent aspects of mental imagery that will be targeted by the Co-MAID intervention (i.e. the control participants feel over their imagery, and the vividness or realness of the images they experience). There were no significant deviations to the protocol in terms of time spent in baseline, treatment or follow up.

Acceptability

Dropout Rate

One participant (PPT03) dropped out of the intervention after session five. This was due to an increase in physical health appointments for multiple comorbid conditions, which made attending psychology sessions unfeasible.

Adherence

All five participants who completed the intervention attended all 9 sessions, giving an overall session attendance rate of 92.6%.

Safety

No serious adverse events were reported.

Completion of Standardised Measures

Completion rates for the GAS-ID, PHQ-9, GAD-7 and PTOS-ID were all 100% at baseline, mid intervention, end of intervention and follow up with no missing data.

The VVIQ was administered to PPT01, PPT02 and PPT03 and replaced with the MIQ-ID after the intervention refinement process. This was due high levels of missing data (average 75% of items not completed) for the VVIQ.

The MIQ-ID replaced the VVIQ and was administered to PPT04, PPT05 and PPT07 and completion rates were 100% with no missing data.

Completion of Daily Mood Ratings

PPT01 completed 99.1% of daily mood recordings. This number was 97.0% for PPT02, 83.6% for PPT03, 100% for PPT04, 99.1% for PPT05 and 55% for PPT07.

Feedback Regarding Aspects of the Intervention

In session 9 of the intervention participants were asked to rate 18 different aspects of the intervention (see Figure 3). Seventeen percent of this data was missing, partly due to some items not being applicable for the participant (e.g. getting to know supporter better not applicable for PPT02). Additional feedback identified aspects of intervention that were experienced as helpful such as using an app to practice breathing exercises regularly and acquiring new skills around imagery and how flexibly these could be used. Three negative aspects of the intervention were identified: (1) needing to complete feedback forms regularly was mentioned by two participants, (2)

having one between session task that reminded one participant of a homework sheet from school (which they did not enjoy completing), and (3) one participant wanted more intervention sessions.

Table 3:

What Was Helpful in Therapy Worksheet Including Endorsements by Participants

Which bits of therapy were helpful?	good  ☐	ok  ☐	bad  ☐
Talking about how I feel	<u>XXX</u>	<u>X</u>	<u>X</u>
Getting to know my supporter better	<u>XXX</u>		
Setting goals for therapy	<u>XXX</u>		<u>XX</u>
Breathing exercises	<u>XXXX</u>		<u>X</u>
Measuring how I feel everyday	<u>XXXX</u>		<u>X</u>
Doing questionnaires	<u>XX</u>	<u>XXX</u>	
Learning about different emotions	<u>XX</u>	<u>XX</u>	
Learning how anxiety feels in my body	<u>XXXX</u>	<u>X</u>	
Learning that how I think changes how I feel	<u>X</u>	<u>XX</u>	
Learning to make mental images	<u>X</u>	<u>XXX</u>	
Doing the calm place exercise	<u>XXX</u>	<u>XX</u>	
Doing the kind helper exercise	<u>XXXX</u>	<u>X</u>	

Doing the switching attention exercise	<u>XXXXX</u>		
Learning to change my mental images	<u>XX</u>	<u>XX</u>	
Practicing new skills	<u>XX</u>	<u>XX</u>	
Making a blueprint	<u>XXXX</u>		
Knowing where to go if I need more help in the future	<u>X</u>	<u>X</u>	
Something else (please write in here) - Filling in one of the homework sheets was stressful and like schoolwork - Liked the location of sessions (not at home) - Didn't like completing feedback forms after each therapy session - 9 sessions was not enough - Used my app to practice breathing every day - It was good to learn how to do the beach relaxation exercise [calm place] because I can use it when I am on the bus			

Semi Structured Qualitative Interviews

Seven superordinate themes were identified from interviews with participants and supporters.

Theme 1: Overall, participants thought the intervention improved mood and functioning

Three participants and three supporters felt the intervention decreased anxiety and was helpful. Participants were described as less anxious with better overall mood. PPT05 was described as engaging more with daily life and less isolated:

"he's gone back to the [person] he used to be... his mood, his engagement with us. He's wanting to go out and do things is...absolutely it's amazing because we were really worried" (SUP05)

PPT02 did not think the intervention helped their mood but enjoyed the sessions.

Theme 2: Having a supporter take part in the intervention

Only PPT02 did not have a supporter and felt it would have been helpful for understanding content. Supporter roles included reminding participants of session timings, transportation, attending sessions, helping with between-session tasks, and sending daily recordings to researchers.

Several participants and supporters noted positive impacts on their relationship. Attending sessions allowed supporters to see how participants navigated new experiences. The therapy created shared goals:

"it strengthened our relationship again because we had sort of lost our way"
(SUP05)

Supporters learned new skills that benefitted them personally and gained better understanding of anxiety's impact on the person they support.

"I would just became more aware of, being mindful of him and and what was going on with him." (SUP05)

Theme 3: Helpful and Unhelpful Aspects of Intervention Format

Some appreciated sessions at home in familiar environments, while others preferred neutral spaces. Individual sessions were beneficial, especially for participants unable to engage with group formats.

Supporters highlighted the importance of flexible, person-centred approaches, allowing irrelevant sections to be skipped while focusing on helpful elements.

“That's what you kind of need, not ‘This is the programme, and we're set in stone’ here. (SUP04)

Participants valued certificates acknowledging their completion. PPT02 framed his certificate.

Theme 4: Experience of Different Intervention Components

Understanding anxiety and its effects was helpful but challenging for some participants:

“Talking about anxiety was hard to do It's a bit hard, bit hard.” (PPT01)

Sessions began with 5-10 minutes of body scans, breathing exercises, and grounding with using essential oils. These were experienced as beneficial:

"he really liked the beginning... He had a lavender smell, and you know, and [therapist]'s calm voice... I think he really benefited from all those kind of things" (SUP04)

Mental imagery components were widely reported as easy to engage with. Participants found generating positive images helpful and accessible:

“He preferred the meditation [calm place exercise]. He definitely liked that kind of thing.” (SUP05)

Some participants found specific between session tasks helpful, though preferences varied (e.g., breathing apps were liked, written homework disliked by PPT04).

Theme 5: Generalising New Skills

Remembering to use skills was challenging for participants, though supporters noted some implementation of techniques in daily life. Having a blueprint to recap and capture intervention information helped retain new skills. Both participants and supporters raised concerns about motivation impacting ability to continue practicing skills independently:

“I think he does remember them [mental imagery skills] and hopefully he will actually use them” (SUP01)

Theme 6: Providing Information to the Study Team

Apps for data collection were helpful, allowing some participants to work independently. Despite five measures at four timepoints, participants weren't overly concerned and mentioned benefits of completing questionnaires. Some participants enjoyed regular mood tracking and found it helped identify improvements. Two said they would continue daily mood logging after research ended.

Theme 7: An Accessible Intervention

Participants and supporters praised the therapist's friendly, engaging approach and ability to explain concepts accessibly for people with learning disabilities.

Accessible materials included video clips, images with text, and audio recordings.

Participants enjoyed making video blueprints, emphasising the collaborative nature.

Apps collected mood data and provided tailored breathing exercises. Participants valued the independence this allowed, and this suggests potential for exploring the use of apps within interventions.

Daily Mood Recordings

Visual representations of daily mood recordings for participants are displayed in Figure 3. Results were analysed using baseline corrected Tau (see Table 4). Daily mood recordings showed a small effect between baseline and intervention for participant one (τ -BC = 0.47, 95% CI [0.19, 0.67]), and these changes were maintained at follow up (τ -BC = 0.44, 95% CI [0.08-0.68]). Participant 2 showed a dip in mood during intervention associated with the illness of his brother (τ -BC = 0.22, 95% CI [-0.08 - 0.47]).

Figure 3:

Daily Ratings of Mood (Dotted Line Distinguishes Baseline, Intervention and Follow Up Phases)

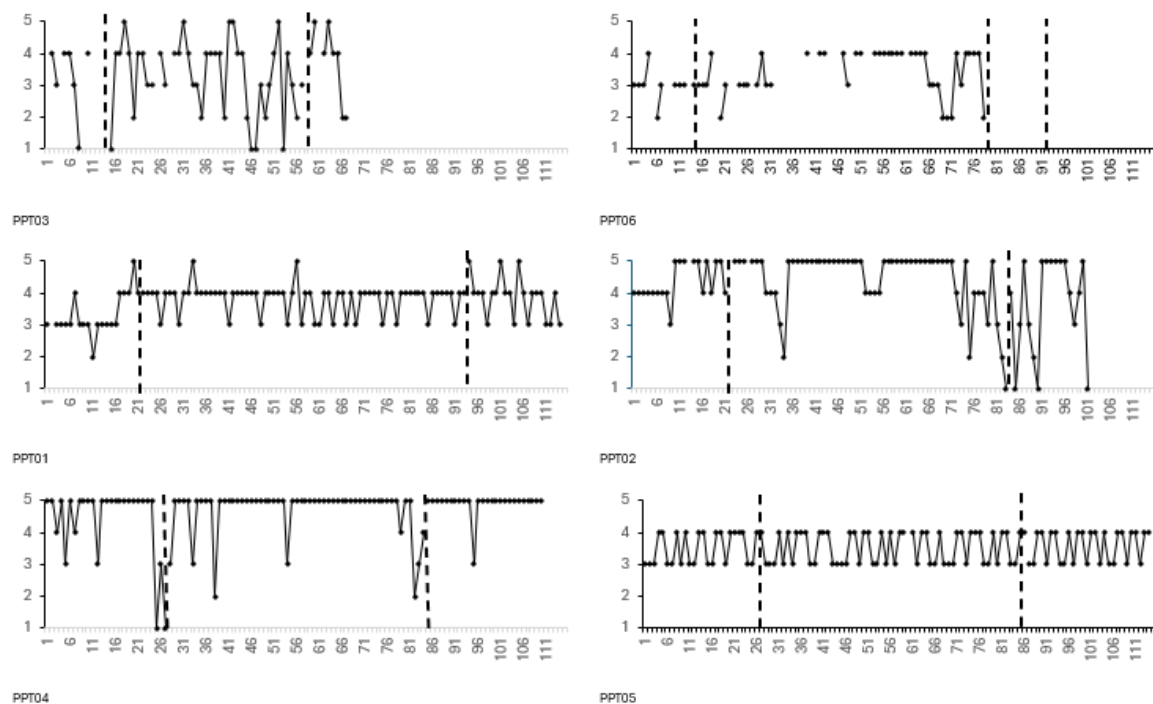


Table 4*Comparison of Daily Mood Recordings at Baseline, Intervention and Follow Up Phases*

Participant	Phase comparison	Tau-BC	Standard error	95% CI
PPT01	A ₁ x B	0.47	0.13	0.19, 0.67
PPT01	B x A ₂	0.02	0.14	-0.25, 0.28
PPT01	A ₁ x A ₂	0.44	0.15	0.08, 0.68
PPT02	A ₁ x B	0.22	0.13	-0.08, 0.47
PPT02	B x A ₂	-0.30	0.15	-0.55, 0.01
PPT02	A ₁ x A ₂	-0.17	0.19	-0.49, 0.19
PPT03	A ₁ x B	0.03	0.21	-0.39, 0.44
PPT03	B x A ₂	0.16	0.21	-0.25, 0.51
PPT03	A ₁ x A ₂	0.21	0.28	-0.34, 0.64
PPT04	A ₁ x B	0.12	0.10	-0.14, 0.37
PPT04	B x A ₂	0.10	0.07	-0.16, 0.35
PPT04	A ₁ x A ₂	0.22	0.10	-0.09, 0.49
PPT05	A ₁ x B	0.05	0.12	-0.20, 0.30
PPT05	B x A ₂	0.04	0.12	-0.22, 0.29
PPT05	A ₁ x A ₂	0.09	0.14	-0.21, 0.37
PPT06	A ₁ x B	0.39	0.14	-0.01, 0.67
PPT06	B x A ₂	missing	missing	missing
PPT06	A ₁ x A ₂	missing	missing	missing

He then showed more variability in his mood towards the end of the intervention when he disclosed a historical attack which was associated with symptoms of Post Traumatic Stress Disorder (PTSD). This mood variability continued over follow up as he waited for an evidence-based intervention for PTSD (τ -BC = -0.30, 95% CI [-0.55- 0.01]). Participant 3 showed mood variability largely in line with his multiple physical health conditions which continued until he dropped out of the intervention (τ -BC = 0.03, 95% CI [-0.39 - 0.44]). Participant 4 may have experienced ceiling effect especially during intervention and follow up phases (τ -BC = 0.10, 95% CI [-0.09 - 0.49]). Participant 5 reported largely stable mood which showed little change across phases (τ -BC = 0.09, 95% CI [-0.21 - 0.37]). The daily mood measure may have been insufficiently fine to capture changes in his mood from day to day. Participant 6 found remembering to record his mood more

challenging, which improved when the daily reminder was changed to mid-day (rather than in the evening) at the suggestion of his supporter. A dip in his mood at the end of intervention was associated with his anxiety about a reduction in support (τ -BC = 0.39, 95% CI [-0.01 - 0.67]). Unfortunately, this participant did not understand the need to continue recording mood over follow up period, so no data were available.

Reliable and Clinically Significant Change

Results for standardised assessments are provided in Table 5. At end of intervention, three participants (50%) reported reliable change on the GAS-ID. All three also met criteria for clinically significant change (PPT01, PPT04 and PPT05). One Participant showed no reliable change (PPT02), and data was missing for one participant (PPT03).

Table 5

Results of Standardised Measures

	Baseline	Mid intervention	End of intervention	Follow up
Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID)				
PPT01	19	15	12	16
PPT02	27	29	24	25
PPT03	19	14	missing	missing
PPT04	22	15	12	13
PPT05	19	9	4	2
PPT06	13	9	9	10
Adapted Patient Health Questionnaire (PHQ-9)				
PPT01	7	6	6	6
PPT02	17	21	20	18
PPT03	3	5		
PPT04	4	2	2	0
PPT05	11	2	1	0
PPT06	8	4	8	4
Adapted Generalized Anxiety Disorder (GAD-7)				
PPT01	3	3	2	3
PPT02	13	16	15	20

PPT03	4	7	missing	missing
PPT04	1	10	0	2
PPT05	11	0	0	0
PPT06	3	4	7	8
Psychological Therapies Outcome Scales – Intellectual Disabilities (PTOS-ID) psychological distress scale				
PPT01	29	27	8	8
PPT02	22	27	34	22
PPT03	29	16	missing	missing
PPT04	8	15	10	9
PPT05	14	2	1	0
PPT06	9	10	19	14
Psychological Therapies Outcome Scales – Intellectual Disabilities (PTOS-ID) psychological wellbeing scale				
PPT01	20	22	24	20
PPT02	30	30	29	28
PPT03	27	23	missing	missing
PPT04	26	30	33	32
PPT05	22	31	29	30
PPT06	20	21	21	22
Vividness of Visual Imagery Questionnaire (VVIQ)				
PPT01	12	missing	28	27
PPT02	58	missing	missing	missing
PPT03	missing	missing	missing	missing
Mental Imagery Questionnaire for People with intellectual disability (MIQ-ID)				
PPT04	missing	15	15	15
PPT05	missing	12	18	19
PPT06	9	6	12	7

Discussion

This study provides initial evidence supporting the acceptability of Co-MAID, a co-designed mental imagery-based anxiety intervention for people with mild to moderate intellectual disabilities. The findings demonstrated that mental imagery techniques can be successfully adapted and implemented with this population, addressing a significant gap in accessible psychological interventions.

The primary aim of the study was to investigate intervention acceptability. Participants rated the therapy as highly acceptable, and with one exception, completed all intervention sessions. Supporters described the intervention as bespoke for people with intellectual disabilities, flexible (and thus able to focus on the most pertinent topics for each participant), and engaging. Participants described enjoying therapy sessions, benefiting from a better understanding of their anxiety and finding exercises around self-soothing (e.g. breathing) and amending mental imagery to be helpful and easy to engage with. There were no serious adverse events. The high session attendance rate (92.6%) and excellent completion rates for standardised measures (100%) indicate strong acceptability of the intervention format and procedures. This is particularly encouraging given the challenges often faced in engaging people with intellectual disabilities in psychological interventions. The qualitative findings further support acceptability, with participants and supporters reporting positive experiences and meaningful improvements in mood and functioning.

After the intervention was completed with the first three participants, it was reviewed and refined and a number of adaptations implemented. Details of all proposed intervention refinements are provided in the supplementary materials.

The secondary aim was to capture data using daily mood recordings and standardised anxiety measures and to examine change pre- and post-intervention. While completion rates for both daily mood recordings and standardised measures were high, daily mood ratings showed significant changes in self-reported daily mood ratings for only one participant (PPT01). The varied patterns in daily mood recordings highlight the complexity of measuring change in this population. While some

participants showed sustained improvements, others experienced mood variability related to external factors such as physical health conditions or disclosing historic traumatic events. This underscores the importance of considering individual circumstances and using multiple outcome measures when evaluating interventions for people with intellectual disabilities. Half of the participants who completed the intervention demonstrating reliable and clinically significant change on the primary outcome measure (GAS-ID). This suggests that the intervention may have been associated with positive changes. This is notable given the brief nature of the intervention (all participants completing the intervention within 9 sessions) compared to traditional CBT approaches that often require more extensive adaptation and longer treatment periods for people with intellectual disabilities.

Limitations

Several limitations should be acknowledged. The small sample size (n=6) and single case experimental design, while appropriate for initial testing, limit generalisability of findings and the conclusions that can be drawn about causality. Whilst the use of randomisation and multiple baselines increased the robustness of the SCED methodology, this type of design, and the loss of a single participant limit the strength of the conclusions that can be drawn. Additionally, the reliance on self-report measures may be problematic for some participants with intellectual disabilities, despite the use of adapted versions. Three of the participants and two supporters taking part in the semi structured interviews had received a refined version of the intervention. The daily mood recordings showed considerable individual variation in completion rates and interpretability, suggesting this outcome measure may need further refinement if it

were to be used in the future. The lack of follow-up data for one participant and the brief follow-up period (2 weeks) also limited our understanding of longer-term effects.

Clinical Implications

Clinically, Co-MAID offers several advantages over traditional verbal-based CBT approaches. Mental imagery techniques appear to pose less cognitive burden while remaining engaging and accessible. The incorporation of multi-sensory elements, visual materials, and technology (such as breathing apps) enhanced accessibility and independence for participants.

The role of supporters emerged as particularly important, with qualitative findings highlighting benefits not only for participants but also for supporter relationships and understanding. This suggests that involving supporters may be a key component for maximising intervention effectiveness and skill generalisation.

The findings suggest several considerations for clinical practice. Developing therapist experience and competence in using mental imagery-based interventions for this population may be of value. How best to incorporate supporter involvement while maintaining appropriate boundaries and consent processes requires consideration.

The accessibility features that contributed to success - visual materials, multi-sensory approaches, flexible pacing, and person-centred adaptation - should be standard elements of implementation. Co-MAID challenges previous assumptions about cognitive limitations and highlights the potential for innovative approaches that build on strengths rather than focusing on deficits. Services may wish to explore integrating brief mental imagery techniques into existing care pathways for people with intellectual disabilities experiencing anxiety.

Theoretical Implications

The success of mental imagery techniques in this population has important theoretical implications. The findings support previous research suggesting that people with intellectual disabilities can engage with and manipulate mental imagery when provided with appropriate support and scaffolding. This challenges assumptions about cognitive limitations and opens new avenues for psychological intervention development.

However, measuring changes in the vividness and control of mental imagery was difficult to do due to a lack of appropriate measures, leading to the development of a new mental imagery questionnaire for this population (the Mental Imagery Questionnaire for people with intellectual disabilities; MIQ-ID). Initial testing of the psychometric properties of this measure is ongoing.

The systematic approach to intervention refinement, guided by the FRAME expanded framework, demonstrates the value of iterative development when working with specific populations. The documented adaptations illustrate the importance of modifying interventions based on participant feedback to enhance acceptability and potentially feasibility.

The flexibility highlighted by supporters as particularly valuable suggests that while manualised interventions provide important structure, maintaining adaptability to individual needs and circumstances is crucial for this population.

Future Research Directions

This initial testing provides a foundation for larger-scale evaluation of Co-MAID. Future research should include a feasibility study with larger samples. Longer follow-up

periods are needed to assess maintenance of progress and identify factors that support implementing and practicing new skills.

Research is also needed to identify which participants are most likely to benefit from mental imagery interventions and to refine eligibility criteria. The role of supporter involvement requires further investigation to determine which areas of the intervention particularly benefit from supporter input.

Other areas for consideration include refining outcome measures for this population, exploring the use of technology in delivering interventions, understanding the active ingredients of the intervention and investigating the optimal intervention dosage.

Conclusion

This study provides encouraging initial evidence that mental imagery-based interventions can be acceptable and effective for people with mild to moderate intellectual disabilities experiencing anxiety.

The co-design process and iterative refinement demonstrate the importance of involving people with intellectual disabilities as partners in intervention development. While further research is needed to establish efficacy and optimal implementation, these findings suggest that mental imagery techniques should be considered as part of the therapeutic toolkit for supporting mental health in people with intellectual disabilities.

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Chapter 7: General Discussion

In this thesis I have reported on a series of studies that described the phenomenon of mental imagery in people with intellectual disability and then used a co-design methodology to develop a novel mental imagery-based anxiety intervention for people with moderate to mild intellectual disabilities. I carried out initial testing of the intervention in NHS settings.

In this discussion chapter I set out key findings from the studies. I describe how results have been disseminated. I described the research findings, and the strengths and limitations of the studies. I then propose theoretical and clinical implications, as well as detailing areas and plans for future research. Finally, I draw some conclusions.

7.1 Summary of Key Findings

In Chapter 2 I report the findings from a systematic review which incorporated literature across fields of clinical, experimental and sports psychology. Forty-one papers were included that described investigations into the use of mental imagery by people with intellectual disabilities. People with intellectual disabilities were able to engage with all types of mental imagery processes (image generation, maintenance, inspection and transformation), in line with the general population. However, there were few studies about the phenomenology of mental imagery. I synthesised various strategies to enhance mental imagery which included ensuring participants understood tasks, providing opportunity to rehearse tasks (including using concrete prompts) and using scaffolding to help participants elaborate their responses.

Given the dearth of information regarding the phenomenology of mental imagery in this population, I conducted a qualitative investigation into the lived experience of mental imagery in people with mild to moderate intellectual disabilities, which I

reported in Chapter 4. I conducted ten individual interviews alongside creative methods and analysed the verbal and visual data used Interpretative Phenomenological Analysis. People with intellectual disabilities could experience and report rich, vivid mental imagery across all sensory modalities.

I reported the findings from a further systematic review of inclusive research methods with people with intellectual disabilities across health and care in Chapter 3. I synthesised the results from 17 studies across a wide range of health and care topics. Inclusive research methods are being used across a diverse range of topics within health and care settings. Researchers with intellectual disabilities took part in a range of research tasks including data collection, analysis and dissemination. I undertook a thematic synthesis of these studies to understand the experiences of inclusive research for both researchers with and without intellectual disabilities. This highlighted the additional burden of inclusive research, whilst simultaneously acknowledging the additional value co-researchers brought to the project, and how much this work was appreciated and recognised by all team members.

Within Chapter 5, I used Experience Based Co-Design (EBCD) to adapt a psychological intervention (called Co-MAID) by working alongside people with intellectual disabilities and other stakeholders. This iterative process involved a series of focus groups, and a workshop event. Through this, we developed and refined a novel intervention, ready to be testing in clinical services. I captured the experiences of people involved in the EBCD process through qualitative and quantitative methods. People enjoyed and valued being actively involved with this process. Their involvement resulted in numerous changes and refinements to the intervention, making it more accessible for the target population.

In Chapter 6 I report the initial testing and subsequent refinement on the intervention. I trialled the intervention with 6 people in NHS clinical services presenting with clinically significant levels of anxiety. I collected measures of daily mood, psychological distress and anxiety symptoms pre and post intervention. I conducted semi structured interviews with participants after the intervention. Co-MAID resulted in some reduction in levels of anxiety post intervention and was acceptable to participants and their supporters. These findings further support the ability of people with mild to moderate intellectual disabilities to engage with mental imagery interventions in real world settings.

7.2 Clinical and Academic Implications

The five studies presented suggest various findings across theoretical, academic and clinical areas.

The Development and Use of Mental Imagery Interventions for People with Intellectual Disabilities

There is a robust evidence-base for the ability of people with intellectual disabilities to engage with both mental imagery and subsequently mental imagery interventions. Whilst some mental imagery-based interventions or techniques have been adapted for use within clinical services, including EMDR (Schipper-Eindhoven et al., 2024), guided relaxation (Dagnan et al., 2018), and various Compassion Focused Therapy based techniques (Brougham et al., 2020), this work suggests that the range and complexity of mental imagery interventions accessible to this population should be reconsidered.

Various mental imagery interventions are being developed in mainstream services, and evidence from this these suggests that a wider range of these may be

suitable and acceptable to people with intellectual disabilities This may include image disrupting interventions such as the use of Tetris (Holmes et al., 2015), and adapted Imagery Rescripting exercises, as explored within Chapter 6.

Within this study, only one person (who was also autistic) was unable to generate any mental imagery. All other participants could engage with several aspects of mental imagery (if not all) and could do this with varying levels of vividness and realness (as would be expected within the general population). Even for those who described no mental imagery when engaging with the study, they were quickly able to develop this skill, when given appropriate support in terms of directions, examples, scaffolding and prompts. Such participants were generally pleased and surprised at this new skill they could then access and enjoyed testing out different ways of manipulating their imagery.

Information about a person's mental imagery should be routinely gathered in assessment sessions. This would allow the therapist to understand the role of any distressing mental imagery and gauge whether the person may be willing and able to engage in therapeutic mental imagery techniques. This may require the therapist to explain what mental images are and the ways in which these may be experienced. Using visual prompts and exercises, and standardised measures of mental imagery for this population (see section 7.6 below) may help explore experiences of mental imagery in assessment sessions.

Using Creative Methods with People with Intellectual Disabilities

Within this project creative methodologies have been used in different phases. The use of visual images created by research participants to represent their experiences of mental imagery in Chapter 3 was novel. These images were analysed using IPA alongside verbal accounts and results synthesised. This demonstrated the use of

creative methods to explore the lived experience of complex internal processes such as mental imagery in populations for whom qualitative methods have sometimes been seen as inaccessible (Rose et al., 2019).

Creative methods (including zines, comics, film, live animation and infographics) have been co-produced with people with intellectual disabilities as part of a wider dissemination strategy. These techniques provide opportunity for enhanced accessibility in terms of making information easier for people with intellectual disabilities to understand (Terras et al., 2021) but also make the process of co-creating dissemination materials easier for those with intellectual disabilities to engage with.

Inclusive Research with People with Intellectual Disabilities

As this study is the first we are aware of to co-design a psychological intervention with people with intellectual disabilities, it provides a template for including people with intellectual disabilities in wider roles throughout the research process, including complex tasks such as analysing qualitative data. There is growing evidence that researchers with intellectual disabilities can engage with complex data analysis tasks around sensitive topics (e.g. Tilley et al., 2022). There remain challenges in ensuring the genuine collaboration of people with intellectual disabilities in research, as discussed in Chapter 4.

Inclusive research or Patient and Public Involvement (PPI) runs the risk of being tokenistic due to the significant burden it places in terms of time and other resources. There is a need to engage with a wide range of people with intellectual disabilities and other stakeholders to ensure a diverse range of views are heard and accommodated. This is both time consuming and requires a proactive stance, with researchers needing to be able to build relationships and sustain them over years.

Use of Technology by People with Intellectual Disabilities

Within the project various technologies were employed to improve accessibility and empower participants to engage autonomously with the intervention and communicate with the research team. These included the use of the Daylio app to communicate with the research team, and the use of apps such as iBreathe to customise breathing exercises, provide prompts to practice these exercises, and as a way of guiding them through breathing exercises. Other uses of technology included making a video blueprint to capture new strategies and skills learned in the intervention and provide an accessible way of retaining this information, which could be accessed independently via a mobile phone and did not require literacy skills.

Several participants mentioned how helpful and enjoyable they found it to record and monitor their mood, and that they would continue to do this after the intervention. More generally, the research team were surprised by the levels of technology literacy amongst participants, with 5 of the 6 participants having access to and using a smart phone or tablet either independently, or with some support.

Adaptations to Improve Accessibility of the Intervention

The Co-MAID intervention was co-designed with people with intellectual disabilities to be as accessible as possible. The iterative design process meant that feedback about all aspects of the intervention was sought from multiple courses at various time points. This allowed the intervention to be shaped to be accessible. Examples of this included importance of the role of supporters, and the use of technology to provide information in ways that required low levels of literacy and promoted autonomy. A review and refinement of the intervention was built in during Study 5 (Chapter 6) to allow for lessons from real world testing in clinical settings to be

formally reviewed and incorporated using the FRAME framework (Wiltsey Stirman et al, 2019). When testing out Co-MAID in NHS settings, participants found the intervention to be accessible and engaging (Chapter 6), due to the iterative and detailed adaptation and refinement process.

7.3 Dissemination Strategy

Although the dissemination of research findings is emphasised as a crucial part in the development of complex interventions (e.g. Skivington et al., 2021), it is often both under reported within academic papers and undervalued by researchers (Addis, 2002). The gap between research completion and the dissemination of findings have implications for the development of evidence-based practice. Arguably, this is even more important in clinical populations such as people with intellectual disabilities, where sharing high quality practice-based evidence (e.g. understanding the adaptations being made to standardised interventions to make them accessible for the population) is essential (Brown et al., 2017). In addition, the amount of funding allocated specifically to research involving people with intellectual disabilities, including co-researchers is limited when compared to other clinical groups (O'Brien et al., 2022) thus making the dissemination of all findings from such studies even more valuable.

Inclusive research should include inclusive dissemination, which uses plain language and ensures dissemination is aimed at those whose lives will be most impacted by the research (Dew & Boydell, 2017; Parent-Johnson & Duncan, 2024). Within this study, we were aware of the need to ensure information about research findings were disseminated as they became available and throughout the project. Additionally, an easy read summary of the project has been compiled and shared (see Appendix 10). Examples of disseminating information in an accessible format at

different stages of the project included holding an afternoon tea for PPI member, stakeholders and research participant 18 months into the project. This included providing accessible written and verbal information about the first three studies (Chapters 2, 3, and 4) alongside copies of the relevant journal articles.

Dissemination was facilitated through a dissemination matrix (see Table 1). This allowed consideration of all stakeholders in the studies and different formats of sharing information (including alternative and accessible formats). Creative methods to disseminate research findings include the development of an infographic (Appendix 1) and easy read document (Appendix 10). A dissemination workshop will be held on 1 October 2025 to discuss these materials and to co-create additional accessible dissemination materials including a film, storyboard and zine. This process will be captured through live animation. These materials, and the process of co-developing dissemination materials using creative methods will be evaluated through focus groups (with stakeholders and people with intellectual disabilities), and written up for publication (Hewitt et al, manuscript in preparation).

Table 1*Dissemination Matrix*

Dissemination Audience	Aim of Dissemination Strategy	How to implement dissemination Strategy	Date Implemented/ Tangible Outputs
Research funders	Communicate to funders that all research outputs identified in project plan have been achieved	Annual funding report delivered to funder detailing community engagement	Funding report delivered March 2023, March 2024, March 2025
	Ensure funders aware of range of research outputs	Detail research outputs (academic publications, community engagement events etc)	Funding report delivered March 2023, March 2024, March 2025
	Funders aware current project has been successfully delivered	Submit final contractual output	Report delivered to funder January 2026
	Provide sufficient evidence for initial promise of intervention to secure additional funding for subsequent feasibility study	Funding application for feasibility study submitted October 2024	Funding for feasibility study secured August 2025
Commissioners of NHS clinical services	Communicate potential of new intervention	Present findings through meetings/ channels attended by commissioners such as Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board	
Research host organisation/ project sponsor	Aware of status of research participants and successful recruitment to target	Update Edge Research Management portal	Recruitment closed on Edge 01/05/2025
	Ensure accurate records regarding status of clinical trial	Update trials registry ISRCTN70980810	To update with publication once accepted Hewitt, O.M., Thompson, P.A., Steel, C. & Langdon, P.E. Initial testing of a novel, mental imagery-

			based anxiety intervention for people with mild to moderate intellectual disabilities using a single case experimental design. This manuscript is currently under peer review with the Journal of Applied Research in Intellectual Disabilities (JARID) submitted 16 July 2025.
	Alert to any ongoing issues with implementing intervention in clinical settings	Regular meetings to feedback with head of Research and Development	Monthly meetings held
Local NHS services (research participants recruited from here)	Ensure services are aware of the intervention that has been delivered to patients	Copy of feedback (easy read) for participants sent to service clinical lead and uploaded to electronic patient notes	12/08/2025
	Ensure relevant electronic patient notes updated in line with department/ Trust standard operating procedures	Update NHS clinical notes for each participant and compile and upload closing letter summarising individual progress through intervention sessions.	By 30 June 2025
	Ensure relevant electronic patient notes updated in line with department/ Trust standard operating procedures	Update risk information as appropriate on patient electronic notes	By 30 June 2025
	Ensure relevant electronic patient notes updated in line with department/ Trust standard operating procedures	Ensure onward referrals made at end of intervention or appropriate closing document completed and patients discharged from service.	By 30 June 2025
	Ensure services are aware of any issues in the delivery of the intervention (implications for	Regular presentations (every 3 months) to update department on study at department research meetings	ongoing

	other research studies recruiting in the department)		
	Ensure services are aware of the intervention that has been delivered to patients	Clinical supervision with service lead to discuss intervention and any issues with participants (throughout duration of intervention delivery)	Completed by 30 June 2025
Community organisations for people with intellectual disabilities (e.g. learning disability partnership board, self-advocacy groups)	Alert organisations to co-designed aspect of intervention plus initial clinical results	Send electronic and hard copies of creative dissemination materials offering to deliver an information session to community organisations	
	Alert organisations to co-designed aspect of intervention plus initial clinical results	Attend local meetings and deliver presentation to describe the project (to be delivered by OH and members of Stakeholder and STAR groups). Include creative dissemination materials as part of presentation	
	Alert organisations to future research opportunities around Co-MAID	Provide information about upcoming feasibility study	
Local/ national charities	Alert organisations to co-designed aspect of intervention plus initial clinical results	Send electronic and hard copies of creative dissemination materials offering to deliver an information session to community organisations	
	Alert organisations to co-designed aspect of intervention plus initial clinical results	Attend local meetings and deliver presentation to describe the project (to be delivered by OH and members of Stakeholder and STAR groups). Include creative	

		dissemination materials as part of presentation	
	Alert organisations to future research opportunities around Co-MAID	Provide information about upcoming feasibility study	
Stakeholders involved as research participants	Feedback aggregated results of study to research participants in accessible format	Create summary sheet of each project and send to all participants who requested feedback	Summary sheet
	Feedback aggregated results of study to research participants in accessible format	Hold community event to disseminate research findings	Event held at community venue 26/03/2025 attended by 12 participants
	Feedback aggregated results of study to research participants in accessible format	Hold community event to disseminate research findings	Event held at community venue 06/09/2022 attended by 20 participants
People with intellectual disability involved as research participants	Feedback aggregated results of study to research participants in accessible format	Create easy read summary sheet of each project and send to all participants who requested feedback	Easy read summary sheet
	Feedback aggregated results of study to research participants in accessible format	Hold community event to disseminate research findings	Event held at community venue 26/03/2025 attended by 12 participants
	Feedback aggregated results of study to research participants in accessible format	Hold community event to disseminate research findings	Event held at community venue 06/09/2022 attended by 20 participants
Clinicians working in field of intellectual disability	Disseminate initial findings including implications for clinical practice (i.e. potential for use of mental imagery components)	Present findings regarding intervention across formats regularly accessed by clinicians	Present information at regional Special Interest Group meeting (5 July 2023), (14 May 2025)
	Share best practice/ innovation (co-design of psychological intervention)	Publish academic article describing how to adapt Experience based Co-Design to develop intervention	Hewitt, O., Langdon, P. E., & Larkin, M. (2025). Using Experience Based Co-Design to Develop a Novel Psychological

			Intervention with People with Intellectual Disabilities and Stakeholders. Journal of Applied Research in Intellectual Disabilities, 38(1), e70022.
Academics working in field of intellectual disability	Update on progress of Co-MAID study	Present at national conference	Hewitt, O (2023, 7-8 December) Improving anxiety in people with mild to moderate intellectual disability: Developing and testing a novel, co-produced, mental imagery intervention. 20th Seattle Club conference, University of Birmingham.
	Update on progress of Co-MAID study	Present at national conference	Hewitt, O. (2024, 12-13 December) Co-maid: co-designing a novel, mental imagery-based intervention for anxiety in people with intellectual disabilities. 21st Seattle Club conference, Kings College London
	Update on progress of Co-MAID study	Present at international conference	Hewitt, O. (2024, 5-8 August) Co-MAID: Co-designing a novel, mental imagery-based intervention for anxiety in people with intellectual disabilities. International Association for the Scientific Study of Intellectual and Developmental Disabilities. 17th world congress, Chicago, USA
	Synthesis literature around inclusive health research for this population	Publish academic article describing systematic review	Hewitt, O., Langdon, P. E., Tapp, K., & Larkin, M. (2023). A systematic review and narrative synthesis of inclusive health and

			social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences? Journal of Applied Research in Intellectual Disabilities, 36(4), 681-701.
	Share evidence base (describe phenomenology of mental imagery in this population)	Publish academic article to report the phenomenology of mental imagery in people with ID	Hewitt, O. M., Langdon, P. E., Hales, S. A., & Larkin, M. (2023). The phenomenology of mental imagery in people with intellectual disabilities. Psychology and Psychotherapy: Theory, Research and Practice, 96(1), 25-39.
	Share best practice/ innovation (co-design of psychological intervention)	Publish academic article describing how to adapt Experience based Co-Design to develop intervention	Hewitt, O., Langdon, P. E., & Larkin, M. (2025). Using Experience Based Co-Design to Develop a Novel Psychological Intervention with People with Intellectual Disabilities and Stakeholders. Journal of Applied Research in Intellectual Disabilities, 38(1), e70022.
	Share novel intervention as addition to literature	Publish academic article describing Single case Experimental Design and process evaluation of intervention	Hewitt, O.M., Thompson, P.A., Steel, C. & Langdon, P.E. Initial testing of a novel, mental imagery-based anxiety intervention for people with mild to moderate intellectual disabilities using a single case experimental design. This manuscript is currently under peer review with the Journal of Applied Research in Intellectual

			Disabilities (JARID) submitted 16 July 2025.
Academics working in field of mental imagery	Share evidence base (establish ability of people with intellectual disability to engage with all aspects of mental imagery)	Publish academic article describing systematic review	Hewitt, O. M., Steel, C., Hales, S. A., Hayden, N., Gundeslioglu, H., Tapp, K., & Langdon, P. (2022). A systematic review and narrative synthesis of mental imagery tasks in people with an intellectual disability: Implications for psychological therapies. <i>Clinical Psychology Review</i> , 96, 102178.
	Share evidence base (describe phenomenology of mental imagery in this population)	Publish academic article to report the phenomenology of mental imagery in people with ID	Hewitt, O. M., Langdon, P. E., Hales, S. A., & Larkin, M. (2023). The phenomenology of mental imagery in people with intellectual disabilities. <i>Psychology and Psychotherapy: Theory, Research and Practice</i> , 96(1), 25-39.
	Update on progress of Co-MAID study	Present at national conference	Hewitt, O. (2024, 23-26 July) Co-MAID: Co-designing a novel, mental imagery-based intervention for anxiety in people with intellectual disabilities. 52nd annual conference of British Association for Behavioural and Cognitive Psychotherapies, Manchester, UK
	Update on progress of Co-MAID study	Present at national conference	Hewitt, O. (2025, 3-6 September) Mental imagery and psychological therapy in people with intellectual disabilities 53rd annual conference of British Association for Behavioural and

			Cognitive Psychotherapies, Glasgow, UK
	Describe initial evidence for use of mental imagery within clinical settings for people with intellectual disabilities and potential impact on clinical symptoms of anxiety	Publish academic article to report initial findings of using Co-MAID in NHS settings	Hewitt, O., Thompson, P.A., Steel, C. & Langdon, P. (in preparation) Initial testing of a novel, mental imagery-based anxiety intervention for people with mild to moderate intellectual disabilities using single case experimental design
	Develop specific measure of mental imagery in people with intellectual disabilities (mental Imagery Questionnaire for people with Intellectual Disabilities; MIQ-ID) and test validity of this	Publish academic article to report development and testing of MIQ-ID	Hewitt, O.M., Steel, C., Thompson, P.A., & Langdon, P.E. (in preparation) The Mental Imagery Questionnaire for People with Intellectual Disabilities (MIQ-ID): development and validation

7.4 Theoretical Implications

Programme Theory

Programme theory describes how an intervention is expected to lead to its effects, and the conditions impacting on this (Skivington et al., 2021). It sets out the key intervention components and how they interact, the mechanisms of the intervention, and describes the context and external factors that may influence or impact the intervention and how it works.

Programme theory for Co-MAID was initially developed alongside key stakeholders at the beginning of the intervention (in line with best practice; Skivington et al., 2021), based on theoretical underpinnings described in Chapter 1. It was subsequently refined and developed at various stages throughout the research project. A key aim of developing a complex intervention when using a theory-based perspective is a refined programme theory (alongside a visual representation of this) (Skivington et al., 2021). This facilitates translation across different contexts, the production of evidence to support the intervention, and understanding that is helpful for decision.

Figure 1

Logic Model for Co-MAID: A Co-Designed Mental Imagery Anxiety Intervention for People with Mild to Moderate Intellectual Disabilities

Key intervention components	Mechanisms	Outcomes (any short, medium, or longer terms outcomes)
Involvement of supporter	Supporter involvement in: • understanding new skills and how to implement them within session • practicing new skills • generalising skills outside of sessions • Creating flow of compassion from other (provides a person to offer affiliation and wisdom). • Creating a safe environment in which to try new experiences.	• Improvement of supporter's understanding of behaviour change and knowledge of intervention • Improved engagement – better understanding of intervention and increased safeness.
Rapport building	• Developing positive therapeutic relationship with family, supporters and clients	• Improved engagement and adherence to intervention from client and network
Assessment	• Establish anxiety as main presenting clinical difficulty • Development of accurate micro formulation that targets distressing imagery	• Ensure appropriateness of Co-MAID intervention • More relevant targeting of distressing imagery • Provision of relevant coping strategies • Better ability to manage client distress in session

Therapist tailors intervention for individual	• Adapting to person's level of understanding, preferences, strengths and needs • Provides scaffolding, modelling and practice to develop mental imagery generation and manipulation skills	• Better understanding of intervention and thus engagement with session content
Psychoeducation (around anxiety and mental imagery)	• Client understands how mental images contribute to and maintain anxiety	• Increased understanding of the role of mental imagery in maintaining anxiety • Better adherence to between session tasks • Spontaneous use of strategies to change mental imagery when experience distressing imagery
Generating compassion focused imagery through kind helper and safe place exercises	• Compassion focused caregiving imagery changes physiology associated with distress through improving self-regulation, downregulating threat system, and increasing soothe system • Experiencing helpful images improves mood	• Increased ability to self-soothe/ settle the mind associated with caregiving • Experience of receiving care increases individual's ability to self soothe
Attention switching exercise	• Grounding aspect brings person into present moment, and facilitates metacognitive perspective (allows person to see their mind rather than being caught up in it) • Taking a different perspective increases flexibility of mind as	• Quietening and settling of the mind and body (increased Soothe system and reduced Threat system) • Increased metacognitive skills (capacity to be able to think about their thoughts) • Improved attentional control and flexibility.

	attention shifted from self-focused imagery to external stimuli • Exposure to anxiety inducing image results in habituation	
Soothing rhythm breathing	• Resonant breathing pattern linked to Improved heart rate variability and greater vagal tone	• Greater vagal tone stimulates the parasympathetic nervous system, leading to feelings of calm and enhanced cognitive functioning (better access to frontal lobes)
Changing properties of an image	• Amended images can be used to replace troublesome images • Understand that images are under conscious control, and that they impact physiology • Changing images can change our physiology to increase soothing states	• Re-evaluate meaning of image and associated distress reduced • Understand images are a product of the mind and not objective reality
Develop competence in using mental imagery techniques	• Shifts in physiological states • Change in meaning of imagery (implicit or explicit) from emotional (felt) sense. • Sense of control over compassionate mental imagery	• Reduction in physiological symptoms of anxiety • Shift in emotional salience of imagery • Increased sense of mastery and control
Completing daily mood recordings	• Enables person to understand and reflect on variability of mood and how these are linked with increased control over mental imagery	• Better understanding how mood fluctuations are linked to external events as well as internal cognitions (e.g. mental images)

Accessible (video) blueprint	• Video blueprint can be accessed independently without any literacy skills • Cued recall of imagery techniques through accessible blueprint aids generalisation	• Ability to revisit and practice skills and materials post intervention
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Assumptions and external factors

- Adaptations and involvement of supporter to facilitate intra session practice
- People with intellectual disabilities were traditionally seen as unable to access psychological therapies, but are generally able to access and amend their mental imagery
- Anxiety may be seen as part of an intellectual disability (diagnostic overshadowing)
- People with intellectual disabilities experience higher rates of anxiety disorders and problems than the general population
- Mental imagery interventions are established in the general population but untested in people with intellectual disabilities
- Anxiety can develop from direct experience and observation of others. It can be maintained through behavioural and cognitive avoidance, worry and rumination.
- Developing a positive therapeutic relationship with the person with intellectual disabilities as well as supporter is essential
- People with intellectual disabilities require adaptations to access some aspects of psychological interventions due to verbal communication and information processing difficulties

makers. A logic model describing aspects of our refined programme theory is presented in Figure 1.

Key Intervention Components

Within the intervention, some aspects were identified as being important to consider when delivering the intervention. These included the role of assessment in ensuring a clinical presentation of anxiety is the main difficulty was emphasised following initial testing in NHS settings, after it became apparent through the course of the intervention that several participants had additional undiagnosed mental health disorders or problems that required different treatment plans (e.g. complex grief reaction).

The need to tailor the intervention to the specific needs and abilities of the individual was noted, and this included adaptations to specific exercises, as well as focusing on some aspects of psychoeducation or skipping irrelevant sections (e.g. some aspects of psychoeducation were too complex for participants with moderate intellectual disabilities).

The accessibility of materials associated with the intervention (including using technology) facilitated engagement with the intervention and with materials after sessions finished.

The ability to record daily mood directly through an app and use this to communicate with the research team also enhanced a sense of mastery and control.

Mechanisms of Change

Within the Co-MAID intervention, various mechanisms of change were identified, some of which occur throughout the intervention, and others specific to mental imagery components. Mechanisms of change will be described in terms various theories including Information Processing and Learning Theories (which underpin CBT) and

Attachment Theory and an evolutionary-informed biopsychosocial model (which underpins CFT) (as appropriate), and cognitive neuroscience.

Therapeutic Relationship

Rapport building with the supporter, client and other members of the network was seen as important. Relational aspects also included identifying and developing a supporter who was able to work with the person with intellectual disabilities to facilitate their involvement with the intervention. The patient's experience in relation to the therapist during therapy sessions (therapeutic alliance) is a critical component of the therapeutic process, and a predictor of treatment outcomes (Snyder & Silberschatz, 2016). Concepts of attunement have roots in Bowlby's attachment theory (Fletcher & Gallichan, 2016). Attunement includes both an ability to connect with another person's experience/sensations (i.e., cognitive and affective empathy), and to communicate that connection to the other person (Erksine, 1998). Both attunement and responsiveness of the therapist to the patient's therapeutic needs is an important predictor of session outcome (Snyder & Silberschatz, 2016).

Psychoeducation

Within the interventions, psychoeducation included understanding the role cognitions play in distress and how thoughts, feelings and behaviours interact (Timulak & McElvaney, 2013). Having a better understanding of what anxiety is (in terms of common cognitions, physiological symptoms and associated behaviours) both allows individuals to understand their own experiences and normalises these experiences as a feature of anxiety disorders and problems (Headley et al., 2024).

Generalising and Maintaining Skills

The intervention addressed issues of generalising and maintaining skills.

Generalisation is an ability to perform a behaviour learned in one context in a different context. People without intellectual disabilities often generalise new skills spontaneously through observing others and direct learning. However, generalising is often difficult for people with intellectual disabilities. Therefore, the intervention included a number of strategies to support generalising of new skills, including through between session tasks, the involvement of the supporter, teaching skills with different instructions or exercises, encouraging the participant to practice skills in different environments. To ensure that changes in behaviour are maintained, the intervention ensured that regular practice of skills meant the person was confident in using it (i.e. they developed mastery), encouraged practice of these skills, and focused on exercises that were meaningful and appealing to the individual (Langdon et al., 2024).

Soothing Rhythm Breathing

The use of several aspects of Compassion Focused Therapy (including the kind helper and safe place exercises, as well as using relaxation and grounding at the start of each session) was thought to lead to increased ability to self soothe and down regulate the individual threat system. Anxiety is conceptualised as an inappropriate threat response that requires regulating through improved affect regulation.

Soothing rhythm breathing stimulates the vagus nerve which increases Heart-Rate Variability (HRV), a marker of ability to respond effectively to stress. Soothing rhythm breathing therefore improves psychological symptoms of anxiety through increased heart rate variability, and better vagal tone (Steffen et al., 2021). Greater vagal tone stimulates the parasympathetic nervous system, leading to feelings of calm and

enhanced cognitive functioning (particularly related to executive functioning) (Dolphin et al, 2022).

When paired with a pleasant smell (such as an aromatherapy oil) soothing rhythm breathing results in enhanced subjective relaxation, slower breathing, and synchronized respiration, fluctuations of heart rate and brain activity (Ghibaud et al., 2024). Within CFT, this is conceptualised as a reduced Threat system and a more activated Soothe system. Soothing Rhythm Breathing may be negatively reinforced as it results in a reduction of aversive symptoms of anxiety. Soothing rhythm breathing can also be conceptualised as a relaxation technique which reduces anxiety symptoms through targeting physiological arousal to produce a relaxation response.

Grounding

The use of a grounding exercise is designed to increase mindfulness, and to target both cognitions and physiological behaviours. It is conceptualised as reducing anxiety through improved attentional monitoring and flexibility, decentering and acceptance. Decentering and acceptance are emotion regulation strategies, with decentering allowing the individual to viewing experiences such as distressing imagery as objective events, and to accept these experiences regardless of their valence (Lindsay & Cresswell, 2017). Attentional monitoring is based within selective and executive control brain networks (Lindsay and Creswell, 2017), and brain regions such as the insula, which is associated with interoception (Treves et al., 2019). The emotion regulation strategies of decentering and acceptance are supported by the default mode and salience networks in the brain (Rahrig et al., 2022).

Mental Imagery Mechanisms of Change

Following refinement of the intervention at mid-point in the testing process, each therapy session started with soothing rhythm breathing and grounding exercises. Three mental imagery components were included in the intervention (generating helpful images, attention switching and changing properties of an image).

Generating Helpful Images

There are several mechanisms through which increasing helpful images can reduce anxiety. Generating positive images is associated with positive affect (Landkroon et al., 2022), which is incompatible with anxiety states. Generating images specifically around compassion focused caregiving changes physiology associated with distress through improving self-regulation. This is achieved through downregulating the Threat system and simultaneously increasing the Soothe system.

The process of engaging in generating helpful images may be reinforced by operant conditioning, either through positive reinforcement (engaging with this activity becomes associated with a positive affect state) or through negative reinforcement (the reduction of the aversive affect state of anxiety).

The experience of receiving care (both within the therapeutic relationship and through nurturing imagery) increases the individual's ability to self soothe and settle their mind (through increased Soothe drive and reduced Threat drive). Practicing these exercises to generate helpful images results in greater feelings (in terms of both somatic symptoms and affect) or calm and less of anxiety, which may reinforce the behaviours of generating helpful images.

Attention switching exercise

The Attention Switching Exercise requires the individual to bring to mind a distressing image, before shifting attention away from this image (generally through

using a grounding exercise in which attention is focused on noises the person can hear, things they can see in the room, smells that are present etc). Several mechanisms of change may be present in this imagery component. Exposure to the anxiety inducing image results in habituation (a core component of exposure therapy). The use of grounding techniques brings the person's awareness into present moment and facilitates metacognitive perspective (allowing them to observe their own mind rather than being caught up in it). Engaging in grounding techniques promote the Soothe system and moving attention away from distressing images reduces the Threat system. Being guided by the therapist to take a different perspective increases the flexibility of the mind, as attention is shifted from self-focused imagery to external stimuli.

Wells's (2000) self-regulatory executive function (S-REF) model suggests that emotional disorders are maintained by the Cognitive Attentional Syndrome (CAS). CAS is characterised by excessive self-focused attention, repetitive negative thinking, heightened focus on threat, and coping strategies that inadvertently maintain distress. Wells suggests metacognitive therapy and attentional training (such as the Attentional Switching Exercise) facilitate disengagement from the CAS by shifting attention away from inflexible self-focused attention, thus promoting detached mindfulness and attentional control. Engaging in the Attention Switching Exercise results in increased Soothe system and a resultant quietening and settling of the mind and body, increased metacognitive skills (capacity to be able to think about their thoughts), and improved attentional control and flexibility.

Changing properties of an image

Cognitive theory suggests cognitions are a key determinant of human behaviour and emotion (Ezawa & Hollon, 2023). Cognitions result from underlying schemas (our

assumptions and attitudes resulting from previous experiences). Individuals with maladaptive schemas subsequently experience bias, unhelpful cognitions which lead to (and maintain) various psychological disorders and problems. It is hypothesized that when these schemas are maladaptive, the associated biased cognitions lead to the development and maintenance of psychopathology (Beck, 2002).

Teaching an individual to change the properties of a mental image, with amended images replacing unhelpful or distressing images, is a form of cognitive restructuring. This may help an individual to understand that their images are under conscious control, and that they impact physiology. Engaging in this exercise may help a person to realise that changing their images can change their physiology or somatic symptoms to increase soothing physiology. Subsequent changes in the meaning of the imagery (either implicit or explicit) may result from changes in their emotional (or felt) sense. This also increases a sense of control over both distressing and compassionate imagery. These processes form part of cognitive reappraisal (Clark, 2022), a key emotion regulation strategy (Gross, 2002).

Increased competence in metacognitive skills (such as changing mental imagery) is associated with mastery and control. Increased metacognitive skills allowed for changes in relationship with images, as participants understood that images can be shaped and changed through conscious control, and are not reflections of things that will happen, or of an external reality. Rather, imagery can be changed at will with resultant changes to affect and behaviours. Noting and understanding variability in daily mood (associated with internal and external events) allowed for links between behaviour, cognition and affect to be established.

Exposure to the distressing image weakens the association between the conditional stimulus (CS) and unconditional stimulus (US) (a core part of exposure therapy. Morina et al. (2017) suggest that the underlying working mechanism of changing the properties of an image might be the change in meaning of the representation of the negative valence of aversive stimuli (Arntz, 2012). Accordingly, instead of weakening the association between the conditional stimulus (CS) and unconditional stimulus (US) as often done in exposure therapy, this technique is proposed to directly target or re-evaluate the distressing image (the unconditional stimulus memories) directly and thus reduce the CS-elicited affect. This also neutralises aversive affect states, reinforcing the technique. Inhibitory learning, whereby new, non-threatening associations are formed with a previously feared stimulus, thus weakening the original fear response, may also be a mechanism by which anxiety is reduced using this technique.

Following the intervention, various metacognitive skills are enhanced. An individual can re-evaluate the meaning of image and thus associated distress is reduced. They understand that images are a product of the mind and not objective reality. Physiological symptoms of anxiety are reduced, along with a shift in the emotional salience of imagery, and an increased sense of mastery and control.

Understanding and testing mechanisms of change in psychological interventions is complex and difficult (Salkovskis et al., 2023). However, understanding intervention specific interventions (such as mental imagery components) can lead to greater symptom change compared with general interventions (such as the therapeutic relationship) and therefore requires careful consideration, and future work to

understand these mechanisms of change more fully, possibly through experimental studies.

Implications for Mental Imagery Theory

Evidence for the applicability of existing models of mental imagery within the population of people with intellectual disabilities will be summarised. Facilitators and barriers to the use of mental imagery in this population will be synthesised, and implications for theories discussed.

Evidence for Mental Imagery in People with Intellectual Disabilities

Kosslyn's (Kosslyn et al., 2006) theory of imagery consists of four components: imagery generation, inspection, maintenance, and transformation. The process of image transformation has been subsequently developed to include image manipulation (Pearson et al., 2013). As well as these four imagery components, as additional component, that of the subjective experience (or phenomenology) of imagery also requires exploration (Pearson et al., 2013). Such mental imagery components are not independent, with several aspects of mental imagery being involved in the experience of having mental images.

This thesis provides evidence for these mental imagery components within the clinical population of people with intellectual disabilities. Chapter 2 detailed a body of evidence that people with intellectual disabilities can and do generate mental images across various situations and tasks. They are as able as the general population to generate images of both random patterns and meaningful images. Using mental imagery consistently improves performance on motor skills tasks in people with intellectual disabilities, although not as much as physical practice, which is in line with the general population. It may be that such tasks are accessible for this population due

to them being specific, concrete and based on real tasks that participants have already seen or experienced (e.g., Hinnell & Virji-Babul, 2004). Kwong (1994) found that whilst people with intellectual disabilities can spontaneously use mental imagery as a memory strategy, additional prompting and scaffolding may be required for them to do this, and for the images they generate to be as clear and distinctive as people without intellectual disability.

In terms of image maintenance, while there is some evidence that people with intellectual disabilities can complete imagery maintenance tasks, and that their image refreshing process is relatively efficient, their abilities may be more limited in terms of the complexity of stimuli. However, the lack of meaningful and personally relevant stimuli in such tasks may affect performance to a greater degree within this population

Image inspection skills on motor-based tasks may be comparable to the general population, but evidence around this skills area is lacking. People with intellectual disabilities may require additional time to learn tasks and show overall slower speed. More concrete tasks (such as motor-based tasks) appear to facilitate mental image inspection.

Evidence regarding the mental image transformation skills of people with intellectual disabilities is mixed, with three studies reporting participants had no deficit in mental transformation, and five studies indicated an overall impairment in this skill. Mental rotation may be particularly difficult for people with intellectual disabilities, when stimuli are presented at 180°, or without a clear axis of elongation. Again, stimuli lacking personal relevance and meaning may be more difficult to engage. It appears that some, if not all, people with intellectual disabilities can perform mental transformation, albeit at a lower level than the general population.

Whilst few studies have explored the phenomenology of mental imagery in people with intellectual disabilities, this was the focus of study three (as described in Chapter 4). This study found that all participants could engage with and report some aspects of mental imagery. Indeed, within the wider thesis, mental imagery has been discussed with 30 people with intellectual disabilities as part of individual and small groups testing out different mental imagery exercises. Only one person has been unable to generate any mental imagery despite scaffolding and prompts. This person had a diagnosis of autism (although it should be noted that many other people with intellectual disabilities and a diagnosis of autism have been able to engage with mental imagery). Study three reported mental imagery of participants with mild to moderate intellectual disability broadly in line with the general population.

Participants in Study 3 could experience complex and rich mental imagery simultaneously across several sensory modalities. Mental imagery across different senses was specifically prompted for, given previous research suggested that participants with intellectual disabilities struggled to experience tactile, olfactory, gustatory or kinaesthetic imagery (despite prompting) (Brown & Bullitis, 2006). Participants subsequently reported rich, detailed mental images, which could be surprising, spontaneous, elicit emotions and experienced across sensory modalities (Hewitt et al., 2023). Their experiences creating, comparing, checking and changing mental images map onto theoretical aspects of mental imagery generation, inspection, maintenance, transformation (Kosslyn et al., 2006), and manipulation (Pearson et al., 2013). The only unrepresented theoretical stage was image maintenance, which occurs at a neural level.

Facilitators and Barriers to Mental Imagery in People with Intellectual Disabilities

Several strategies are described within the literature to support and enhance the mental imagery of this population. Making instructions understandable to participants was essential. Children with intellectual disabilities did not benefit from a simple instruction to generate their own mental imagery (Gibson et al., 1995), which may imply that they require more specific and individualised guidance. People with intellectual disabilities may be less aware of the concept of mental imagery (although this was also the case for several participants without intellectual disability) and may require simplified and more specific, detailed instructions to both understand the concept of mental imagery, and generate mental images (Brown & Bullitis, 2006). This was also reported in Study Three, with some participants being initially unaware that they could experience or control mental imagery. Adapting instructions to the person's cognitive and emotional level improves accessibility, including the use of materials designed for children, with appropriate adaptations (Mevissen, Lievegoed, & De Jongh, 2011). Such adaptations may include producing instructions in easy read format and using visual imagery to enhance participants' understanding of verbal material (Hardiman et al., 2018).

Making the imagery task more concrete improves accessibility. This included using physical prompts through which participants could explore and practice a task, before transferring to completing such tasks in their heads (Hinnell & Virji-Babul, 2004). Other strategies included discussing mental images with a client in detail to make them more accessible before drawing out these images on paper with clients (Kroese & Thomas, 2006) and talking participants through a practice mental image task to ensure they understand the concept of generating mental images (de la Iglesia et al., 2005).

Both of these strategies were helpfully employed in Study Three. Using concrete prompts and aids to facilitate mental imagery, including photographs (Brown & Bullitis, 2006), drawings, pictures (Dilly, 2014) and physical objects (Mevissen, Lievegoed, Seubert, & De Jongh, 2011) could be helpful, and the use of images was reported within Study Three.

In Kosslyn's computational theory of imagery (Kosslyn, 1980; Kosslyn et al., 2006), image maintenance is achieved by the re-activation of visual memory representations in an Object Properties Processing subsystem. One consequence of this shared neural substrate is that mental images can be disrupted by concurrent visual processing (Quinn & McConnell, 2006). Reducing external visual stimulation, through asking participants to shut their eyes, can facilitate mental imagery (Brown & Bullitis, 2006). This strategy was found to be helpful by several participants in Study Three.

Providing extra practice sessions and trials to ensure participants had correctly understood and learned the task was described in several studies (e.g., Hinnell & Virji-Babul, 2004). Participants with intellectual disabilities requires additional trials to learn the task, reduce the number of errors they made, and demonstrate improved performance (Wilen, 1982). Without such additional time, their results may be inaccurate, with poor performance being due to unfamiliarity with the demands of the task, rather than underlying cognitive deficits (Roskos-Ewoldsen et al., 2006). Additional sessions in which the concept of mental imagery is explicitly explained, and practice exercises completed together, rather than assuming participants with intellectual disabilities already understand this concept can be helpful (Hinnell & Virji-Babul, 2004; Screws & Surburg, 1997) and was included within Study Three.

Participants benefited from additional scaffolding to help shape and elaborate their responses and provide more correct responses. Strategies included using specific, rather than open ended probes (Jens et al., 1990) or cues, in the form of specific questions (Gordon et al., 1994). Study Three found that the use of both open and closed questions was beneficial in facilitating mental imagery. Study Three also reported that the emotional salience of images can both facilitate mental imagery and may also act as a barrier (if images are distressing or unwanted).

Theoretical Implications

Whilst people with intellectual disabilities are generally able to engage in all aspects of Kosslyn's model of mental imagery, it can be difficult to tease mental imagery deficits from verbal comprehension difficulties (understanding tasks and instructions) and verbal fluency (reporting the experience of mental imagery). This requires careful consideration to ensure experiments are valid.

Within Study Three, mental imagery could be surprising for participants as well as the interviewer. Several participants did not recognise the concept of mental imagery and denied ever experiencing mental imagery including daydreams (as found by Brown & Bullitis, 2006). This is commonly found within the general and clinical populations and is why mental imagery should be specifically asked about at assessment (Holmes et al., 2019), rather than relying on spontaneous self-report. However, participants willingly attempted various mental imagery exercises and could engage with such tasks. They seemed both pleased and surprised and occasionally would check they had retained this skill after the interview. Mental imagery could be unexpected, as when mental images transformed spontaneously. Mental imagery is

both unbidden and deliberately constructed in the general population (Pearson et al., 2015).

Several participants spontaneously shared their internal experience of mental imagery with the interviewer in Study Three, through consulting with them about changing their image, and using physical (gesturing the shape of a rainbow) or auditory (making the noise of a seagull) cues. Participants shared their internal experiences with the interviewer to build rapport and used mental imagery as a relational tool.

Study Three reported that engaging with mental images elicited a range of powerful emotions including joy, disgust and fear, as found in the general population, and people undergoing psychological interventions (Skottnik & Linden, 2019). Brown and Bullitis (2006) reported several participants declined to image actions such as climbing a stepladder (due to fear of heights), concluding that mental imagery elicits associated emotions in people with intellectual disabilities. Such findings are in line with Pearson et al. (2015) who found that visual mental imagery activates the same neural circuits as perceptual information, but in a weaker form.

As mentioned, the emotional saliency of items could both facilitate and impede a participant's engagement with mental imagery. Participants in Study Three engaged more willingly with preferred objects, although not universally, as when a participant imagined a much-loved cat going into her bedroom (unallowed) and experienced a visceral reaction of outrage. Understanding why and when participants engage with various imagery is essential, as it may be erroneously assumed that not engaging with imagery is due to cognitive difficulties. Mental imagery can be emotional (as in this example) or non-emotional (e.g. mentally rotating an abstract figure) (O'Donnell et al., 2020). The lack of meaningful, emotionally salient stimuli used in mental imagery tasks

comparing the performance of people with intellectual disabilities with aged-matched controls (e.g. Meneghetti et al., 2018) may partially account for poorer engagement and performance from people with intellectual disabilities.

The ease and mastery with which participants engaged in mental imagery existed on a continuum. Whilst all participants could engage in some mental imagery, most required scaffolding to build detail, in line with Brougham et al. (2020). However, a couple of participants who provided detailed mental imagery without prompting, reported frequent, spontaneous mental imagery in everyday life. For several participants, mental imagery was difficult to generate and explore, requiring frequent prompting. The general population experience a range of mental imagery abilities, with a small proportion experiencing aphantasia (no mental imagery) (Keogh & Pearson, 2018). Level of cognitive ability did not seem related to mastery over mental imagery, with some of the more cognitively able participants struggling with this.

7.5 Strengths and Limitations of the Study

This thesis reports the development and testing of a novel psychological intervention that results from the fusion of experiential and empirical evidence, rooted in psychological theory, in line with guidance for developing complex interventions (MRC and NIHR framework for developing complex interventions; Skivington et al., 2021). Theoretical underpinnings of the intervention have been described, and a comprehensive programme theory, including mechanisms of change, has been developed and refined throughout the research.

Throughout the development and execution of this project, there has been a genuine involvement and collaboration with people with intellectual disabilities, from a

range of backgrounds and lived experiences. The involvement of various stakeholders throughout all stages of the research process has also enriched the process and allowed for the experiences of people with more severe intellectual disabilities to be represented. Meaningful co-research with people with severe and profound intellectual disabilities remains complex and challenging, despite novel, creative approaches being developed (e.g. Warwick, 2020). The lack of accessibility (both in terms of the methodologies employed in these research studies, and in the final intervention) for people with severe and profound intellectual disabilities is acknowledged as a limitation. Work to improve the accessibility of psychological interventions for this population is essential and ongoing (e.g. Jahoda et al., 2024; Langdon et al., 2024).

The initial testing of the intervention in NHS clinical services is reported in Chapter 6. Whilst the use of randomisation and multiple baselines within the SCED design added to the strength of the methodology, the small sample size in this study is a limitation. Whilst the use of the Daylio app allowed several participants to report their daily mood measures directly to the research team (and participants found the process of monitoring their mood to be helpful and enjoyable), daily mood records lacked consistency for most participants to ensure a stable baseline. Conversely for one participant (PPT05), their daily mood recordings appeared to lack variability, making the impact of the intervention difficult to ascertain from daily measures, and for PPT04, ceiling effects again appeared to hamper the results of the intervention being demonstrated through this data. Testing in real world settings provided initial evidence that the intervention can be easily translated into current NHS provision for this client group. Additional information about the need to ensure clear inclusion and exclusion criteria for eligible participants has been gleaned which will allow the intervention to be

targeted to those most likely to benefit (rather than those presenting with additional mental health disorders or problems, of which anxiety is a symptom, rather than the main presenting issue).

Initially, the intervention used the Vividness of Visual Imagery Questionnaire (VVIQ; Marks, 1973) to evaluate the participant's ability to engage with aspects of mental imagery at baseline, mid intervention, end of intervention and at two week follow up. The VVIQ is a 16-item questionnaire, with high levels of repetition. It was not developed or validated with people with intellectual disabilities and was chosen due to the lack of appropriate mental imagery measures available. However, after the initial testing of the intervention with three participants, it became apparent that participants were refusing to engage with this measure, finding it repetitive and too long. As a result, I developed a new mental imagery questionnaire specifically for this population (Mental Imagery Questionnaire for People with Intellectual disabilities; MIQ-ID), and I am currently validating this measure (Hewitt, Steel et al., in preparation).

A robust and extensive dissemination strategy was developed to address the needs of a wide range of stakeholders. This work allowed us to both engage with and benefit from peer review across multiple sources. We are now co-producing a range of creative dissemination materials with people with intellectual disabilities. These include an easy read document, an infographic, a comic, film/ video material, a zine, and live animation materials (see Appendix 10 for an example of draft materials). This work will be formally evaluated through a series of focus groups to capture the experiences of taking part in such dissemination activities for both people with intellectual disabilities and stakeholders. Findings will be disseminated through an academic publication (Hewitt et al., manuscript in preparation) and a webpage to collate and distribute these materials.

Despite the comprehensive dissemination strategy, more recent research suggests that researchers should move beyond dissemination to knowledge translation and consider using a framework such as PARiHS to guide and evaluate knowledge translation activities (e.g. Kitson & Harvey, 2016). The emerging field of knowledge translation challenges researchers to think beyond traditional ways of producing and disseminating research to increase research integrity, uptake, and applicability (Dew & Boydell, 2017). An integrated approach underpinned by a recognised conceptual framework and a sound plan that identifies the aims, stakeholders, main messages, and strategies. knowledge translation should ensure the inclusion of end users (people with intellectual disabilities and those who support them) throughout the research process (Kothari & Wathen, 2013).

This thesis reports a range of studies using various methodologies. The author's epistemological stance is outlined in Chapter 1. Throughout the process of conducting these studies, a reflexive log was maintained, to document the research process, help to identify my own biases and assumptions, and enhance the trustworthiness of the studies (especially those using qualitative methods), through increased transparency (Ortlipp, 2008). I found this log especially helpful in understanding and documenting my thoughts, questions and decisions around the research, and found that the process of writing out these notes clarified my thought process and allowed the rationale for decisions around aspects of research (e.g. decisions about design or reflections regarding analysis) to become visible to myself. This became more pertinent when conducting several studies during the Covid-19 pandemic, which curtailed face to face data collection and meetings. Whilst I was able to use the process of writing (as well as capturing material for my reflexive log through voice notes and other audio recordings

which were then transcribed and added to the log) to develop my thoughts and questions, which I then shared with supervisors, co-researchers and others, this writing was not directly shared with other members of the research team. Its primary aim was to facilitate my reflective stance. Appendix 9 contains various excerpts from this reflexive log.

7.6 Future Research Directions

This series of research studies provide avenues for future research, both generally within the fields of inclusive research, and more specifically relating to mental imagery in people with intellectual disabilities, and the Co-MAID intervention.

Evidence from other clinical populations, such as children and adolescents (Pile et al., 2021), suggest that mental imagery interventions might facilitate the effectiveness of cognitive approaches but not vice versa, this making imagery interventions an important part of a combination treatment approach (Holmes et al., 2018).

The use of inclusive research methods to co-design a psychological intervention with people with intellectual disabilities, suggests that this is a feasible and useful methodology and one that should be considered more widely by researchers. The need for appropriate research training for co-researchers with intellectual disabilities was highlighted in Chapter 3, and would facilitate this approach (Tuffrey-Wijne, 2020), although the appropriateness of a standardised training programme needs careful consideration (Walmsley et al., 2018).

The lack of an appropriate measure of mental imagery for people with intellectual disabilities has been highlighted as an area of need in terms of both

understanding the capabilities of people with intellectual disabilities to engage with mental imagery, evaluating mental imagery based clinical interventions, and measuring change in mental imagery interventions in a research context. An adapted measure of Mental Imagery in People with Intellectual Disabilities (Hewitt et al., in preparation) has been developed and is currently undergoing validation within this population. This measure may facilitate clinicians in gathering information about their client's mental images during assessment and allow this clinically relevant information to feed through to formulation and subsequent interventions.

The use of creative methodologies to disseminate research findings in accessible ways alongside co-researchers with intellectual disabilities has been explored but there remains scope for this area to be developed. No research has yet looked at co-researchers with intellectual disabilities who have participated in developing and disseminating such materials, and this is an area ripe for research. The continuing dissemination of this study, and a formal evaluation of co-researchers' experiences of these creative dissemination strategies will be a valuable addition to the literature (Hewitt et al, in preparation).

Whilst some initial promise has been shown that Co-MAID can reduce levels of anxiety in people with mild to moderate intellectual disabilities in clinical settings, the effectiveness of the intervention can only be demonstrated through a definitive trial. Before such work can be undertaken, a feasibility study is required with a larger sample size to demonstrate if it would be feasible to conduct a randomised controlled trial of this intervention. To this end, a feasibility study of Co-MAID will begin in February 2026, funded by the National Institute for Health and Care Research (NIHR) through the

Research for Patient Benefit scheme (NIHR208933). This will involve 40 participants and will be conducted across 5 NHS Trusts.

Additional areas of research, potentially using experimental paradigms, would test each mental imagery component within the intervention, to further understand mechanisms of change, and which intervention components produced the most powerful change on affect (either in isolation or in combination). Results would feed into an updated programme theory and logic model.

7.7 Conclusions

The genuine and meaningful involvement of people with intellectual disabilities throughout the research processes presented has created a more accessible intervention. This was reflected in the high levels of engagement and acceptability of the intervention. Throughout this project, it was found that people with intellectual disabilities are willing to engage with research and enjoyed doing so. They valued contributing to the process and found it to be an important use of their time. They also felt that their contribution was valued by researchers.

The focus of formal frameworks and processes to develop and refine the intervention add rigour and credibility to the work presented and suggest good practice for other researchers developing complex interventions with this population.

It has been important for me to capture the voices and experiences of people with intellectual disabilities throughout the project and to represent this in academic outputs produced to date. I am looking forward to engaging with my co-researchers in a range of creative methods to disseminate our findings and writing about this process for other researchers to learn from.

Co-MAID is a promising intervention, using novel and innovative strategies for this population. The prospect of working with co-researchers to test the feasibility of this intervention is exciting, both for those it may directly impact, and for developing the range of evidence based psychological interventions available to this marginalised group of people.

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Appendix 1: Infographic Summarising Project



Appendix 2: Search Strategy (Study 1)

A Systematic Review and Narrative Synthesis of Mental Imagery Tasks in People with an Intellectual Disability: Implications for Psychological Therapies [search strategy]

Manuscript version: Supplementary Information

The version presented here is a Supplementary Information that may be later published elsewhere.

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Resource Type	Platform	Name of Resource	Resource specific terms
Electronic database	Through HDAS	CINAHL	Subject headings in electronic disability development disability
Electronic database	Through HDAS	MedLine	MeSH in electronic disability persons intellectual disability learning disability development disability learning disability Imager Psychotherapy
Electronic database	Through HDAS	AMED	Subject headings learning disability mental retardation imager relationship analysis
Electronic database	Through Ovid Online	Embase	Subject headings in electronic impairment learning disorder mental deficiency imager
Electronic database	Through HDAS	PsychInfo	Thesaurus terms In electronic Development In electronic Development Disorder Learning Disabilities Learning Disorders
Electronic database	Through HDAS	BNI	Thesaurus terms In electronic Development In electronic Development Disorder Learning Disabilities Learning Disorders
Registers		Cochrane Central Register of Controlled Trials (CENTRAL)	MeSH terms Developmental Disabilities In electronic Disability Learning Disabilities
Grey literature	British Library	ETHoS	

Grey literature		Google Scholar	
Electronic Database	Through Web of Science	Conference proceedings Index	

full search strategy study1

CINAHL

Group A

1. Subject heading *"INTELLECTUAL DISABILITY"/ 2.
- Subject heading *"DEVELOPMENTAL DISABILITIES"/
3. intellectual* N1 disab* ab,ti.
4. learning disab* ab,ti.
5. intellectual* deficient* ab,ti.
6. intellectual* retard* ab,ti.
7. intellectual* impair* ab,ti.
8. intellectual handicap* ab,ti.
9. intellectual* subnormal* ab,ti.
10. learning deficient* ab,ti.
11. learning impair* ab,ti.
12. learning retard* ab,ti.
13. learning subnormal* ab,ti.
14. learning handicap* ab,ti.
15. mental* retard* ab,ti.
16. mental* deficient* ab,ti. 17. mental* handicap* ab,ti.
18. mental* disab* ab,ti.
19. mental* impair* ab,ti.
20. mental* subnormal* ab,ti.
21. intellectual developmental disab* ab,ti.
22. intellectual development disorder* ab,ti.
23. down* syndrome ab,ti.
24. profound* multiple learning disab* ab,ti.
25. profound* intellectual* multiple disab* ab,ti.
26. pervasive developmental* disorder* ab,ti.
27. pervasive developmental* disorder* otherwise specified ab,ti.
28. special education* need* ab,ti.
29. special need* ab,ti.
30. special education* need* disabilit* ab,ti.
31. special need* disabilit* ab,ti.
32. developmental* disab* ab,ti.
33. developmental* disorder* ab,ti.

34. developmental* delay* ab,ti.
35. developmental* difficult* ab,ti.
36. developmental* impair* ab,ti.
37. developmental* handicap* ab,ti.
38. developmental* retard* ab,ti.
39. developmental* subnormal* ab,ti.
40. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40

Group B

41. Image* ab,ti.
42. Mental representation* ab,ti.
43. observer perspective ab,ti.
44. mental imag* ab,ti.
45. mental imagery perspectives ab,ti.
46. mental practice ab,ti.
47. imagery measur* ab,ti.
48. imagery assessment ab,ti.
49. intrusive memor* ab,ti.
50. subjective imag* ab,ti.
51. imag* generat* ab,ti.
52. imag* maintenance ab,ti.
53. imag* inspection ab,ti.
54. imag* transform* ab,ti.
55. visu* working memor* ab,ti.
56. spatial working memor* ab,ti.
57. eidetic imag* ab,ti.
58. guided imag* ab,ti.
59. image* rescript* ab,ti.
60. compassion focused therapy ab,ti.
61. compassion ab,ti.
62. relax* therap* ab,ti.
63. compassio* imag* ab,ti.
64. self-sooth* task ab,ti.
65. visualis* ab,ti.
66. meditation ab,ti.
67. eye movement desensitization and reprocessing ab,ti.
68. EMDR ab,ti.
69. flash forward ab,ti.
70. Flash black ab,ti.

71. pain manage* psychol* ab,ti.
72. hypnosis intellectual disabil* ab,ti.
73. image generation task ab,ti.
74. image maintenance task ab,ti.
75. image scanning task ab,ti.
76. map scanning task ab,ti.
77. mental rotation ab,ti.
78. prospective imag* ab,ti.
79. imag* restruct* ab,ti.
80. imag* reinterpret* ab,ti.
81. imag* exposur* ab,ti.
82. positiv* imag* generat* ab,ti.
83. Episodic simulation ab,ti.
84. 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83
85. 40 and 84

Limit to published date 1 January 1980 to date of search (2021)

MEDLINE

Group A

- 1 *"INTELLECTUAL DISABILITY"/
- 2 *"PERSONS WITH MENTAL DISABILITIES"/
- 3 *"LEARNING DISABILITIES"/
- 4 *"DEVELOPMENTAL DISABILITIES"/
- 5 (intellectual* disab*).ti,ab
- 6 (learning disab*).ti,ab
- 7 (intellectual* deficient*).ti,ab
- 8 (intellectual* retard).ti,ab
- 9 (intellectual* impair*).ti,ab
- 10 (intellectual* handicap*).ti,ab
- 11 (intellectual* subnormal*).ti,ab
- 12 (learning deficient*).ti,ab
- 13 (learning retard*).ti,ab
- 14 (learning subnormal*).ti,ab

- 15 (learning handicap*).ti,ab
- 16 (mental* retard*).ti,ab
- 17 (mental* deficient*).ti,ab
- 18 (mental* handicap*).ti,ab
- 19 (mental* disab*).ti,ab
- 20 (mental* subnormal*).ti,ab
- 21 (intellectual developmental disab*).ti,ab
- 22 (intellectual development disorder*).ti,ab
- 23 (profound* multiple learning disab*).ti,ab
- 24 (profound* intellectual* multiple disab*).ti,ab
- 25 (pervasive developmental* disorder*).ti,ab
- 26 (pervasive developmental* disorder* otherwise specified).ti,ab
- 27 (special education* need*).ti,ab
- 28 (special education* need* disabilit*).ti,ab
- 29 (special need* disabilit*).ti,ab
- 30 (developmental* disab*).ti,ab
- 31 (developmental* handicap*).ti,ab
- 32 (developmental* retard*).ti,ab
- 33 (developmental* subnormal*).ti,ab

Group B

- 34 *"IMAGERY, PSYCHOTHERAPY"/
- 35 (Mental representation*).ti,ab
- 36 (observer perspective).ti,ab
- 37 (mental imag*).ti,ab
- 38 (mental imagery perspectives).ti,ab
- 39 (imagery measur*).ti,ab
- 40 (imagery assessment).ti,ab
- 41 (intrusive memor*).ti,ab
- 42 (imag* maintenance).ti,ab
- 43 (imag* inspection).ti,ab

- 44 (eidetic imag*).ti,ab
- 45 (image* rescript*).ti,ab
- 46 (compassion focused therapy).ti,ab
- 47 (compassion).ti,ab
- 48 (compassio* imag*).ti,ab
- 49 (self-sooth* task).ti,ab
- 50 ("eye movement desensitization and reprocessing").ti,ab
- 51 (EMDR).ti,ab
- 52 (flash forward).ti,ab
- 53 (Flash-black).ti,ab
- 54 (pain manage* psychol*).ti,ab
- 55 (hypnosis intellectual disabil*).ti,ab
- 56 (image generation task).ti,ab
- 57 (image maintenance task).ti,ab
- 58 (image scanning task).ti,ab
- 59 (map scanning task).ti,ab
- 60 (mental rotation).ti,ab
- 61 (imag* restruct*).ti,ab
- 62 (imag* reinterpret*).ti,ab
- 63 (Episodic simulation).ti,ab
- 64 (1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33)
- 65 (OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63)
- 66 (64 AND 65)
- 67 66 [DT 1980-2021]

AMED

Group A

1. Subject headings learning disabilities
2. Subject headings mental retardation
3. intellectual* adj1 disab*ab,ti.
4. learning adj1 disab*ab,ti.
5. intellectual* adj1 deficient* ab,ti.
6. intellectual* adj1 retard* ab,ti.
7. intellectual* adj1 impair* ab,ti.
8. intellectual* adj1 handicap* ab,ti.
9. intellectual* adj1 subnormal* ab,ti.
10. learning adj1 difficult* ab,ti.
11. learning adj1 deficient* ab,ti.
12. learning adj1 impair* ab,ti.
13. learning adj1 retard* ab,ti.
14. learning adj1 subnormal* ab,ti.
15. learning adj1 handicap* ab,ti.
16. mental* adj1 retard* ab,ti.
17. mental* adj1 deficient* ab,ti.
18. mental* adj1 handicap* ab,ti.
19. mental* adj1 disab* ab,ti.
20. mental* adj1 impair* ab,ti.
21. mental* adj1 subnormal* ab,ti.
22. intellectual adj1 developmental adj1 disab* ab,ti.
23. intellectual adj1 development adj1 disorder* ab,ti.
24. down* adj1 syndrome ab,ti.
25. profound* adj2 multiple adj1 learning adj1 disab* ab,ti.
26. profound* adj1 intellectual* adj1 multiple adj1 disab* ab,ti.
27. pervasive adj1 developmental* adj1 disorder* ab,ti.
28. pervasive adj1 developmental* adj1 disorder* adj2 otherwise specified ab,ti.
29. special adj1 education* adj1 need* ab,ti.
30. special adj1 need* ab,kw,sh,ti.
31. special adj1 education* adj1 need* adj2 disabilit* ab,ti.
32. special adj1 need* adj2 disabilit* ab,ti.
33. developmental* adj1 disab* ab,ti.
34. developmental* adj1 disorder* ab,ti.
35. developmental* adj1 delay* ab,ti.
36. developmental* adj1 difficult* ab,ti.
37. developmental* adj1 impair* ab,ti.
38. developmental* adj1 handicap* ab,ti.
39. developmental* adj1 retard* ab,ti.
40. developmental* adj1 subnormal* ab,ti.
41. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40

Group B

42. Subject heading imager
43. Subject heading relation 44. Subject heading is relation
45. Image* ab,ti.
46. Mental representation* ab,ti.
47. observer perspective ab,ti.
48. mental imag* ab,ti.
49. mental imagery perspectives ab,ti.
50. mental practice ab,ti.
51. imagery measur* ab,ti.
52. imagery assessment ab,ti.
53. intrusive memor* ab,ti.
54. clinical imag* ab,ti.
55. subjective imag* ab,ti.
56. imag* generat* ab,ti.
57. imag* maintenance ab,ti.
58. imag* inspection ab,ti.
59. imag* transform* ab,ti.
60. visu* working memor* ab,ti.
61. spatial working memor* ab,ti.
62. eidetic imag* ab,ti.
63. imag* deficit ab,ti.
64. guided imag* ab,ti.
65. image* rescript* ab,ti.
66. compassion focused therapy ab,ti.
67. compassion ab,ti.
68. relax* adj1 therap* ab,ti.
69. compassio* imag* ab,ti.
70. self-sooth* task ab,ti.
71. visualis* ab,ti.
72. meditation ab,ti.
73. emotion desensitization and reprocessing ab,ti.
74. EMDR ab,ti.
75. flash forward ab,ti.
76. Flash-black ab,ti.
77. pain manage* adj6 psychol* ab,ti.
78. hypnosis adj6 intellectual disabil* ab,ti.
79. image generation task ab,ti.
80. image maintenance task ab,ti.
81. image scanning task ab,ti.
82. map scanning task ab,ti.
83. mental rotation ab,ti.

84. prospective imag* ab,ti.
85. imag* restruct* ab,ti.
86. imag* reinterpret* ab,ti.
87. imag* exposur* ab,ti.
88. imag* reduct* ab,ti.
89. positiv* imag* generat* ab,ti.
90. menta* synthes* ab,ti.
91. Episodic simulation ab,ti.
92. 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 or 91
93. 41 and 92

Limits publication year 1980-2021

Embase

Group A

1. Subject heading intellectual impairment.mp. or *intellectual impairment/
2. Subject heading learning disorder.mp. or *learning disorder/ 3. Subject heading mental deficiency.mp. or *mental deficiency/
4. learning adj1 disab* ab,ti.
5. intellectual* adj1 deficien* ab,ti.
6. intellectual* adj retard* ab,ti.
7. intellectual* adj1 impair* ab,ti.
8. intellectual* adj1 handicap* ab,ti. 9. intellectual* adj1 subnormal* ab,ti.
10. learning adj1 difficult* ab,ti.
11. learning adj1 deficien* ab,ti.
12. learning adj1 impair* ab,ti.
13. learning adj1 retard* ab,ti.
14. learning adj1 subnormal* ab,ti.
15. learning adj1 handicap* ab,ti.
16. mental* adj1 retard* ab,ti.
17. mental* adj1 deficien* ab,ti. 18. mental* adj1 handicap* ab,ti.
19. mental* adj1 disab* ab,ti.
20. mental* adj1 impair* ab,ti.
21. mental* adj1 subnormal* ab,ti.
22. intellectual adj1 developmental adj1 disab* ab,ti.
23. intellectual adj1 development adj1 disorder* ab,ti.
24. down* adj1 syndrome ab,ti.
25. profound* adj2 multiple adj1 learning adj1 disab* ab,ti.
26. profound* adj1 intellectual* adj1 multiple adj1 disab* ab,ti.

27. pervasive adj1 developmental* adj1 disorder* ab,ti.
28. pervasive adj1 developmental* adj1 disorder* adj2 otherwise specified ab,ti.
29. special adj1 education* adj1 need* ab,ti.
30. special adj1 need* ab,ti.
31. special adj1 education* adj1 need* adj2 disabilit* ab,ti.
32. special adj1 need* adj2 disabilit* ab,ti.
33. developmental* adj1 disab* ab,ti.
34. developmental* adj1 disorder* ab,ti.
35. developmental* adj1 delay* ab,ti.
36. developmental* adj1 difficult* ab,ti.
37. developmental* adj1 impair* ab,ti.
38. developmental* adj1 handicap* ab,ti.
39. developmental* adj1 retard* ab,ti.
40. developmental* adj1 subnormal* ab,ti.
41. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41

Group B

42. Subject heading imagery.mp. or *imagery/ or guided imagery/
43. Image* ab,ti.
44. Mental representation* ab,ti.
45. observer perspective ab,ti.
46. mental imag* ab,ti.
47. mental imagery perspectives ab,ti.
48. mental practice ab,ti.
49. imagery measur* ab,ti.
50. imagery assessment ab,ti.
51. intrusive memor* ab,ti.
52. clinical imag* ab,ti.
53. subjective imag* ab,ti.
54. imag* generat* ab,ti.
55. imag* maintenance ab,ti.
56. imag* inspection ab,ti.
57. imag* transform* ab,ti.
58. visu* working memor* ab,ti.
59. spatial working memor* ab,ti.
60. eidetic imag* ab,ti.
61. imag* deficit ab,ti.
62. guided imag* ab,ti.
63. image* rescript* ab,ti.
64. compassion focused therapy ab,ti.
65. compassion ab,ti.

66. relax* adj1 therap* ab,ti.
67. compassio* imag* ab,ti.
68. self-sooth* task ab,ti.
69. visualis* ab,ti.
70. meditation ab,ti.
71. eye movement desensitization and reprocessing ab,ti.
72. EMDR ab,ti.
73. flash forward ab,ti.
74. Flash-black ab,ti.
75. pain manage* adj6 psychol* ab,ti.
76. hypnosis adj6 intellectual disabil* ab,ti.
77. image generation task ab,ti.
78. image maintenance task ab,ti.
79. image scanning task ab,ti.
80. map scanning task ab,ti.
81. mental rotation ab,ti.
82. prospective imag* ab,ti.
83. imag* restruct* ab,ti.
84. imag* reinterpret* ab,ti.
85. imag* exposur* ab,ti.
86. imag* reduct* ab,ti.
87. positiv* imag* generat* ab,ti.
88. menta* synthes* ab,ti.
89. Episodic simulation ab, ti.
90. 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89
91. 42 and 90

Limits publication year 1980-2021

PsychInfo

Group A

1. MAINSUBJECT Intellectual Development
2. MAINSUBJECT Intellectual Development Disorder
3. MAINSUBJECT Learning Disabilities
4. MAINSUBJECT Learning Disorders
5. intellectual* disab* ab,ti.
6. learning disab* ab,ti.
7. intellectual* deficient* ab,ti.
8. intellectual* retard* ab,ti.
9. intellectual* impair* ab,ti.

10. intellectual* handicap* ab,ti.
11. intellectual* subnormal* ab,ti.
12. learning difficult* ab,ti.
13. learning deficient* ab,ti.
14. learning impair* ab,ti.
15. learning retard* ab,ti.
16. learning subnormal* ab,ti.
17. learning handicap* ab,ti.
18. mental* retard* ab,ti.
19. mental* deficient* ab,ti.
20. mental* handicap* ab,ti.
21. mental* disab* ab,ti.
22. mental* impair* ab,ti.
23. mental* subnormal* ab,ti.
24. intellectual developmental disab* ab,ti.
25. intellectual development* disorder* ab,ti.
26. down* syndrome ab,ti.
27. profound* multiple learning disab* ab,ti.
28. profound* intellectual* multiple disab* ab,ti.
29. pervasive developmental* disorder* ab,ti.
30. pervasive developmental* disorder* otherwise specified ab,ti.
31. special education* need* ab,ti.
32. special need* ab,ti.
33. special education* need* disabilit* ab,ti.
34. special need* disabilit* ab,ti.
35. developmental* disab* ab,ti.
36. developmental* disorder* ab,ti.
37. developmental* delay* ab,ti.
38. developmental* difficult* ab,ti.
39. developmental* impair* ab,ti.
40. developmental* handicap* ab,ti.
41. developmental* retard* ab,ti.
42. developmental* subnormal* ab,ti.
43. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42

Group B

44. Image* ab,ti.
45. Mental representation* ab,ti.
46. observer perspective ab,ti.
47. mental imag* ab,ti.
48. mental imagery perspectives ab,ti.

49. mental practice ab,ti.
50. imagery measur* ab,ti.
51. imagery assessment ab,ti.
52. intrusive memor* ab,ti.
53. subjective imag* ab,ti.
54. imag* generat* ab,ti.
55. imag* maintenance ab,ti.
56. imag* inspection ab,ti.
57. imag* transform* ab,ti.
58. visu* working memor* ab,ti.
59. spatial working memor* ab,ti.
60. eidetic imag* ab,ti.
61. imag* deficit ab,ti.
62. guided imag* ab,ti.
63. image* rescript* ab,ti.
64. compassion focused therapy ab,ti.
65. compassion ab,ti.
66. relax* therap* ab,ti.
67. compassio* imag* ab,ti.
68. self-sooth* task ab,ti.
69. visualis* ab,ti.
70. meditation ab,ti.
71. eye movement desensitization and reprocessing ab,ti.
72. EMDR ab,ti.
73. flash forward ab,ti.
74. Flash black ab,ti.
75. pain manage* psychol* ab,ti.
76. hypnosis intellectual disabil* ab,ti.
77. image generation task ab,ti.
78. image maintenance task ab,ti.
79. image scanning task ab,ti.
80. map scanning task ab,ti.
81. mental rotation ab,ti.
82. prospective imag* ab,ti.
83. imag* restruct* ab,ti.
84. imag* reinterpret* ab,ti.
85. positiv* imag* generat* ab,ti.
86. Episodic simulation ab, ti.
87. 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57
OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 OR 66 OR 67 OR 68 OR 69 OR 70
OR 71 OR 72 OR 73 OR 74 OR 75 OR 76 OR 77 OR 78 OR 79 OR 80 OR 81 OR 82 OR 83
OR 84 OR 85 OR
86

88. 43 and 87

Publication date after this date 1 January 1980

BNI

Group A

1. MAINSUBJECT.EXACT(Intellectual disabilities)
2. MAINSUBJECT.EXACT(Developmental disabilities)
3. intellectual* disab* ab,ti.
4. Learning disab*ab,ti.
5. intellectual* deficien* ab,ti.
6. intellectual* retard* ab,ti.
7. intellectual* impair* ab,ti.
8. intellectual* handicap* ab,ti.
9. intellectual* subnormal* ab,ti.
10. learning difficult* ab,ti.
11. learning deficien* ab,ti.
12. learning impair* ab,ti.
13. learning retard* ab,ti.
14. learning subnormal* ab,ti.
15. learning handicap* ab,ti.
16. mental* retard* ab,ti.
17. mental* deficien* ab,ti. 18. mental* handicap* ab,ti.
19. mental* disab* ab,ti.
20. mental* impair* ab,ti.
21. mental* subnormal* ab,ti.
22. intellectual developmental disab* ab,ti.
23. intellectual development* disorder* ab,ti.
24. down* syndrome ab,ti.
25. profound* multiple learning disab* ab,ti.
26. profound* intellectual* multiple disab* ab,ti.
27. pervasive developmental* disorder* ab,ti.
28. pervasive developmental* disorder* otherwise specified ab,ti.
29. special education* need* ab,ti.
30. special need* ab,ti.
31. special education* need* disabilit* ab,ti.
32. special need* disabilit* ab,ti.
33. developmental* disab* ab,ti.
34. developmental* disorder* ab,ti.
35. developmental* delay* ab,ti.
36. developmental* difficult* ab,ti.
37. developmental* impair* ab,ti.
38. developmental* handicap* ab,ti.

- 39. developmental* retard* ab,ti.
- 40. developmental* subnormal* ab,ti.
- 41. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15
OR
16 OR 17 OR 18o 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR
29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41
OR 42

Group B

- 42. Image* ab,ti.
- 43. Mental representation* ab,ti.
- 44. observer perspective ab,ti.
- 45. mental imag* ab,ti.
- 46. mental imagery perspectives ab,ti.
- 47. mental practice ab,ti.
- 48. imagery measur* ab,ti.
- 49. imagery assessment ab,ti.
- 50. intrusive memor* ab,ti.
- 51. subjective imag* ab,ti.
- 52. imag* generat* ab,ti.
- 53. imag* maintenance ab,ti.
- 54. imag* inspection ab,ti.
- 55. imag* transform* ab,ti.
- 56. visu* working memor* ab,ti.
- 57. spatial working memor* ab,ti.
- 58. eidetic imag* ab,ti.
- 59. imag* deficit ab,ti.
- 60. guided imag* ab,ti.
- 61. image* rescript* ab,ti.
- 62. compassion focused therapy ab,ti.
- 63. compassion ab,ti.
- 64. relax* therap* ab,ti.
- 65. compassio* imag* ab,ti.
- 66. self-sooth* task ab,ti.
- 67. visualis* ab,ti.
- 68. meditation ab,ti.
- 69. eye movement desensitization and reprocessing ab,ti.
- 70. EMDR ab,ti.
- 71. flash forward ab,ti.
- 72. Flash black ab,ti.
- 73. pain manage* psychol* ab,ti.
- 74. hypnosis intellectual disabil* ab,ti.
- 75. image generation task ab,ti.

76. image maintenance task ab,ti.
77. image scanning task ab,ti.
78. map scanning task ab,ti.
79. mental rotation ab,ti.
80. prospective imag* ab,ti.
81. imag* restruct* ab,ti.
82. imag* reinterpret* ab,ti.
83. positiv* imag* generat* ab,ti.
84. Episodic simulation ab,ti.
85. 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84
86. 43 and 85

Publication date after this date 1 January 1980

Cochrane Central Register of Controlled Trials (CENTRAL)

Group A

1. MeSH term Developmental Disabilities
2. MeSH term Intellectual Disabilities
3. MeSH term Learning Disabilities
4. Intellectual disability* ab,ti,kw
5. Intellectual Development Disorder ab,ti,kw
6. Mental retard* ab,ti,kw
7. Development disorder* ab,ti,kw
8. mental deficiency* ab,ti,kw
9. Psychosocial Mental Retardation ab,ti,kw
10. Persons with Mental Disabilit* ab,ti,kw
11. learning disability ab i k
12. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11

Group B

13. Image ab i kw
14. Mental representation ab i kw
15. mental image ab i kw
16. imagery assessment ab i kw
17. intrusive memories ab i kw
18. image generation ab i kw
19. image maintenance ab i kw
20. image inspection ab i kw
21. image transformation ab i kw
22. guided image ab i kw
23. image rescript ab i kw

24. compassion foc sed herap ab i kw
25. is alis ab i kw
26. medi a ion ab ikw
27. e e mo emen desensi i a ion and reprocessing ab,ti.kw
28. EMDR ab ikw
29. flash for ard ab i kw
30. flash black ab ikw
31. pain manage AND ps chol ab i kw
32. image scanning asks ab ikw
33. 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27
or 28 or 29 or 30 or 31 or 32
34. 12 and 33

Limit published after 1980

ETHoS

Search an ord learning disabili OR in ellec al disabili AND men al Imager

Google Scholar

(intellectual disability OR learning disability) AND mental imagery

Limit to 1980-present

Sort by relevance

Screen first 100 results

Conference Proceedings Index

Group A

1. TS=intellectual disability
2. TS=Learning Disabilities
5. TS=Intellectual Development Disorder
6. TS=Mental retardation
7. TS=Development disorder
8. 1 or 2 or 3 or 4 or 5 or 6 or 7

Group B

9. TS=mental image
10. TS=mental imagery
11. TS=Mental representation
12. TS=guided imag*
13. TS=compassion focused therapy

14. TS=eye movement desensitization and reprocessing
15. TS=EMDR
16. TS=image scanning tasks
17. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18. 8 and 17

Limit published after 1980

Appendix 3: Quality Appraisal by Study Design (Study 2)

80%> good categories is overall 'good' rating

80%-50% good categories given overall 'mixed' rating

50%< good categories given overall 'poor' rating

JBIRCT checklist (n=9)

Added a question 14 – were ethical issues considered (informed consent, ethical approval for study from appropriate committee?)

	First author (year)	Was true randomisation used?	Was allocation to treatment groups concealed?	Were treatment groups similar at baseline?	Were participants blinded to treatment assignment?	Were those delivering treatment blinded?	Were outcome assessors blinded?	Treatment groups treated identically except for intervention	Follow up completed? If not differences described and analysed?	Participants analysed in the groups they were randomised to?	Outcomes measured in same ways for treatment groups?	Outcomes measured in reliable way?	Appropriate stats used?	Trial design appropriate (and deviations accounted for)?	Ethical issues considered?	Overall?
13	Gibson (1995)	Yes	Unclear	Yes	Unclear	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Mixed
17	Hemayatlab (2010)	Yes	Unclear	Unclear	Unclear	No	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	No	Poor
20	Jens (1990)	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Mixed

21	Karatzas (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Good
29	Poretta (1995)	Yes	Unclear	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Mixed
33	Screws (1997)	Yes	Unclear	Unclear	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Mixed
35	Surburg (1991)	Yes	Unclear	Unclear	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Mixed
36	Surburg (1995)	Yes	Unclear	Unclear	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Mixed
39	Wilen (1982)	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Mixed

JB1 quasi experimental checklist (n=15)

Added a question 10 – were ethical issues considered (informed consent, ethical approval for study from appropriate committee?)

	First author (year)	Clear which is cause and which effect?	Participants included in comparisons similar?	Comparison on participants received similar treatment except for intervention of interest?	Comparison on group?	Multiple measures of outcome before and after intervention?	Follow up completed?	Comparison on outcomes measured similarly?	Outcomes measured in reliable way?	Appropriate stats?	Ethical issues considered?	Overall
6	Campione (1985)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Good
7	Courbois (1996)	Yes	Unclear	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	No	Mixed
8	Courbois (2007)	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	Yes	No	Good
9	de la Iglesia (2004)	Yes	Yes	Yes	No	Not applicable	Yes	Yes	Yes	Yes	No	Mixed
10	de la Iglesia (2005)	Yes	Yes	Yes	No	Not Applicable	Yes	Yes	Yes	Yes	No	Mixed
15	Gordon (1994)	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	Yes	Yes	Good
19	Hinnell (2004)	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	Yes	No	Good

20	Ikeda (2014)	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	Yes	Yes	Good
23	Kwong (1994)	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	Yes	Good
24	Leevers (1998)	Yes	Yes	Yes	No	Not applicable	Not applicable	Yes	Yes	Yes	Yes	Good
25	Meneghetti (2018)	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	Yes	Yes	Good
31	Rickard (1984)	No	Unclear	Yes	No	Not applicable	Not applicable	Yes	Unclear	Unclear	No	Poor
33	Roskos-Ewoldsen (2006)	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	No	Good
38	Uecker (1994)	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	Yes	No	Good
39	Vicari (2006)	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	Yes	Yes	Good

JBI cross sectional (n=3)

Added a question 9 - were ethical issues considered (informed consent, ethical approval for study from appropriate committee?)

	First author (year)	Criteria for inclusion clearly defined?	Study subjects and setting described in detail?	Exposure measured in valid and reliable way	Objective, standard criteria used to measure condition?	Confounding factors identified?	Strategies to deal with confounding factors stated?	Outcomes measured in valid and reliable way?	Appropriate stats?	Ethical issues considered?	Overall
2	Borys (1980)	Yes	Yes	Yes	Yes	No	Not applicable	Unclear	Yes	No	Mixed
11	Di Nuovo (2018)	No	Unclear	No	Yes	No	No	Unclear	Yes	Yes	Poor
12	Doerr (2021)	Yes	Yes	Yes	Yes	No	Not applicable	Yes	Yes	Yes	Mixed

JBİ Qualitative checklist (n=4)

	First author (year)	Congruity between stated philosophical perspective and research methodology	Congruity between research methodology and research question/objectives?	Congruity between research methodology and methods used to collect data?	Congruity between research methodology and representation and analysis of data?	Congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice-versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical? Ethical approval?	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall
3	Brougham (2020)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Good
4	Brown (2006)	Unclear	Yes	Unclear	No	Unclear	No	No	Yes	Yes	Yes	Poor
16	Hardiman (2018)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Good
22	Karatzi (2019)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	Good

JB case reports checklist (n=8)

Added a question 9 (Were ethical issues considered - informed consent, ethical approval for study from appropriate committee?)

	First author (year)	Demographic characteristics clear?	History presented?	Current clinical condition described?	Diagnostic test/assessments described?	Intervention clearly described?	Post-intervention condition described?	Any adverse events identified and described?	Ethics?	Takeaway lessons?	Overall
1	Barrowcliff (2015)	Unclear	Yes	Unclear	Yes	Yes	Yes	No	No	Yes	Mixed
11	Dilly (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Good
17	Hart (2014)	No	No	Yes	Unclear	Yes	Yes	Yes	Unclear	Unclear	Poor
26	Mevissen (a) (2011)	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes	Good
27	Mevissen (b) (2011)	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Good
28	Mevissen (2012)	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Good
32	Rodenburg (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Good
35	Stenfert Kroese (2006)	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Good

Reichow single case design (n=2)

Added a question – were ethical issues considered (informed consent, ethical approval for study from appropriate committee?)

		Selection Bias		Performance Bias		Detection Bias					Overall
	First author (year)	Sequence generation	Participant selection	Blinding of participants and personnel	Procedural fidelity	Blinding of outcome assessors	Selective outcome reporting	Dependent variable reliability	Data sampling	Ethical issues considered	
5	Buhler (2014)	Unclear	Yes	No	Yes	No	Yes	Unclear	Yes	Yes	Mixed
29	Mevisse n (2017)	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Mixed

Appendix 4: Full Search Strategy (Study 2)

Manuscript version: Supplementary Information

The version presented here is a Supplementary Information that may be later published elsewhere.

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A systematic review and narrative synthesis of inclusive research involving people with intellectual disabilities : implications for health research [search strategy]

Hewitt, Olivia, Langdon, Peter, Tapp, Katherine and Larkin, Michael

2021

Coventry, UK: University of Warwick; Warwick Medical School. (Unpublished).

<https://wrap.warwick.ac.uk/160232>

[warwick.ac.uk/lib-publications](https://wrap.warwick.ac.uk/160232)

Search Strategy 27 September 2021

Resource Type	Platform	Name of Resource	Resource specific terms	Total results
Electronic databases	Through HDAS	CINAHL	Subject headings: "intellectual disability", "developmental disabilities"	2524
	Through HDAS	MedLine	MeSH "intellectual disability", "persons with mental disabilities", "learning disabilities", "developmental disabilities", "learning disabilities", MeSH term "COMMUNITY BASED PARTICIPATORY RESEARCH MeSH "CITIZEN SCIENCE"	1765
	Through HDAS	AMED	Subject headings: "learning disability", "mental retardation", "PATIENT PARTICIPATION"/ OR "DECISION MAKING"/"	177
	Through HDAS	Embase	Subject headings: "intellectual impairment", "learning disorder", "mental deficiency", "imagery"	329
	Through HDAS	PsychInfo	MeSH terms: Group A "Intellectual Development", "Intellectual Development Disorder", "Learning Disabilities", "Learning Disorders" Group B "Patient participation" "Community participation" "Stakeholder participation" "Social participation" "action research"	3003

			participatory action research	
	Through HDAS	BNI	MeSH term "LEARNING DISABILITIES" MeSH term "DEVELOPMENTAL DISABILITIES"	360
	Web of Science		((ALL=(intellectual disability)) OR ALL=(learning disability)) AND (ALL=(action research) OR ALL=(inclusive research)) OR ALL=(participatory research)	3426
	EBSCO	Education research complete	(intellectual disability or mental retardation or learning disability or developmental disability or learning disabilities) AND (coproduction or collaboration or collaborative or co-design) OR action research methodology	7494
Grey literature	British Library	ETHoS	(Learning disabilities OR intellectual disabilities) AND co-production, inclusive research	2
		Google Scholar	(Intellectual disability OR learning disability) AND (participatory research OR inclusive research)	First 100 results included

CINAHL

Group A

1. Subject heading "INTELLECTUAL DISABILITY"/ 2. Subject heading "DEVELOPMENTAL DISABILITIES"/
3. (intellectual* disab*).ab,ti.
4. (learning disab*).ab,ti.

5. (intellectual* deficient*).ab,ti.
6. (intellectual* retard*).ab,ti.
7. (intellectual* impair*).ab,ti.
8. (intellectual* handicap*).ab,ti.
9. (intellectual*subnormal*).ab,ti.
10. (learning difficult*).ab,ti.
11. (learning deficient*).ab,ti.
12. (learning impair*).ab,ti.
13. (learning retard*).ab,ti.
14. (learning subnormal*).ab,ti.
15. (learning handicap*).ab,ti.
16. (mental* retard*).ab,ti.
17. (mental* deficient*).ab,ti.
18. (mental* handicap*).ab,ti.
19. (mental* disab*).ab,ti.
20. (mental* subnormal*).ab,ti.
21. (intellectual developmental disab*).ab,ti.
22. (intellectual development disorder*).ab,ti.
23. (down* syndrome).ab,ti.
24. (profound* multiple learning disab*).ab,ti.
25. (profound* intellectual* multiple disab*).ab,ti.
26. (pervasive developmental* disorder*).ab,ti.
27. (pervasive developmental* disorder* otherwise specified).ab,ti.
28. (special education* need*).ab,ti.
29. (special education* need* disabilit*).ab,ti.
30. (special need* disabilit*).ab,ti.
31. (developmental* disab*).ab,ti.
32. (developmental* disorder*).ab,ti.
33. (developmental* delay*).ab,ti.
34. (developmental* handicap*).ab,ti.
35. (developmental* retard*).ab,ti.
36. (developmental* subnormal*).ab,ti.
37. (1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15
OR
OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29
OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38)

Group B

Inclusive research:

38. MeSH term "CONSUMER PARTICIPATION"/
39. MeSH "ACTION RESEARCH"
40. Community participation

41. Stakeholder participation
42. Participatory action research
43. Co-creat*
44. Cocreat*
45. Community-Based Participatory Research
46. CBPR
47. Evidence based co design
48. EBCD
49. Co-produc*
50. Coproduc*
51. Co-design
52. Codesign
53. Participatory design
54. User-center* design
55. Consumer Participa*
56. Client Participa*
57. Emancipatory research
58. Participatory action research
59. Inclusive research
60. Patient participation
61. Citizen science
62. Public engagement
63. Public participant involvement

(40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 OR 66 OR 67 OR 68 OR 69) 39 AND 70

Limit to published date 1 January 2020 to date of search (2021)

MEDLINE

- | | | | |
|----|--------------------------------------|----|----------------------------------|
| 1 | *"INTELLECTUAL DISABILITY"/ | | |
| 2 | *"PERSONS WITH MENTAL DISABILITIES"/ | | |
| 3 | *"LEARNING DISABILITIES"/ | | |
| 4 | *"DEVELOPMENTAL DISABILITIES"/ | | |
| 5 | (intellectual* disab*).ab,ti. | | |
| 6 | (learning disab*).ab,ti. | | |
| 7 | (intellectual* deficien*).ab,ti. | | |
| 8 | (intellectual* retard*).ab,ti. | | |
| 9 | (intellectual* impair*).ab,ti. | | |
| 10 | (intellectual* handicap*).ab,ti. | 11 | (intellectual*subnormal*).ab,ti. |
| | (learning difficult*).ab,ti. | 12 | |
| 13 | (learning deficien*).ab,ti. | | |

- 14 (learning impair*).ab,ti.
- 15 (learning retard*).ab,ti.
- 16 (learning subnormal*).ab,ti.
- 17 (learning handicap*).ab,ti.
- 18 (mental* retard*).ab,ti.
- 19 (mental* deficient*).ab,ti. 20 (mental* handicap*).ab,ti.
- 21 (mental* disab*).ab,ti.
- 22 (mental* subnormal*).ab,ti.
- 23 (intellectual developmental disab*).ab,ti.
- 24 (intellectual development disorder*).ab,ti.
- 25 (down* syndrome).ab,ti.
- 26 (profound* multiple learning disab*).ab,ti.
- 27 (profound* intellectual* multiple disab*).ab,ti.
- 28 (pervasive developmental* disorder*).ab,ti.
- 29 (pervasive developmental* disorder* otherwise specified).ab,ti.
- 30 (special education* need*).ab,ti.
- 31 (special education* need* disabilit*).ab,ti.
- 32 (special need* disabilit*).ab,ti.
- 33 (developmental* disab*).ab,ti.
- 34 (developmental* disorder*).ab,ti. 35 (developmental* delay*).ab,ti.
- 36 (developmental* handicap*).ab,ti. 37 (developmental* retard*).ab,ti.
- 38 (developmental* subnormal*).ab,ti.
- 39 (1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15
OR
16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28
OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38)

Group B inclusive research

- 40 MeSH term "COMMUNITY BASED PARTICIPATORY RESEARCH
- 41 MeSH "CITIZEN SCIENCE"
- 42 Community participation
- 43 Stakeholder participation
- 44 Participatory action research
- 45 Co-creat*
- 46 Cocreat*
- 47 Community-Based Participatory Research
- 48 CBPR
- 49 Evidence based co design
- 50 EBCD
- 51 Co-produc*
- 52 Coproduc*
- 53 Co-design

- 54 Codesign
- 55 Participatory design
- 56 User-center* design
- 57 Consumer Participa*
- 58 Client Participa*
- 59 Emancipatory research
- 60 Participatory action research
- 61 Inclusive research
- 62 Patient participation
- 63 Citizen science
- 64 Public engagement
- 65 Public participant involvement
- 66 (40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65)
- 67 39 AND 66
- 68 67 limit date 2000-2021

AMED

Group A

1. Subject headings "learning disability" 2. Subject headings "mental retardation" 3. (intellectual* disab*).ab,ti.
4. (learning disab*).ab,ti.
5. (intellectual* deficien*).ab,ti.
6. (intellectual* retard*).ab,ti.
7. (intellectual* impair*).ab,ti.
8. (intellectual* handicap*).ab,ti.
9. (intellectual*subnormal*).ab,ti.
10. (learning difficult*).ab,ti.
11. (learning deficien*).ab,ti.
12. (learning impair*).ab,ti.
13. (learning retard*).ab,ti.
14. (learning subnormal*).ab,ti.
15. (learning handicap*).ab,ti.
16. (mental* retard*).ab,ti.
17. (mental* deficien*).ab,ti. 18. (mental* handicap*).ab,ti.
19. (mental* disab*).ab,ti.
20. (mental* subnormal*).ab,ti.

21. (intellectual developmental disab*).ab,ti.
22. (intellectual development disorder*).ab,ti.
23. (down* syndrome).ab,ti.
24. (profound* multiple learning disab*).ab,ti.
25. (profound* intellectual* multiple disab*).ab,ti.
26. (pervasive developmental* disorder*).ab,ti.
27. (pervasive developmental* disorder* otherwise specified).ab,ti.
28. (special education* need*).ab,ti.
29. (special education* need* disabilit*).ab,ti.
30. (special need* disabilit*).ab,ti.
31. (developmental* disab*).ab,ti.
32. (developmental* disorder*).ab,ti.
33. (developmental* delay*).ab,ti.
34. (developmental* handicap*).ab,ti.
35. (developmental* retard*).ab,ti.
36. (developmental* subnormal*).ab,ti.
37. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40

Group B inclusive research

38. MeSH term "PATIENT PARTICIPATION" OR " DECISION MAKING"
39. Community participation
40. Stakeholder participation
41. Participatory action research
42. Co-creat*
43. Cocreat*
44. Community-Based Participatory Research
45. CBPR
46. Evidence based co design
47. EB CD
48. Co-produc*
49. Coproduc*
50. Co-design
51. Codesign
52. Participatory design
53. User-center* design
54. Consumer Participa*
55. Client Participa*
56. Emancipatory research
57. Participatory action research
58. Inclusive research
59. Patient participation

60. Citizen science
61. Public engagement
62. Public participant involvement
63. (40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65)
64. 39 AND 66
65. 67 limit date 2000-2021

Embase

Group A

1. Subject heading intellectual impairment.mp. or *intellectual impairment/
2. Subject heading learning disorder.mp. or *learning disorder/ 3. Subject heading mental deficiency.mp. or *mental deficiency/ 4. (intellectual* disab*).ab,ti.
5. (learning disab*).ab,ti.
6. (intellectual* deficien*).ab,ti.
7. (intellectual* retard*).ab,ti.
8. (intellectual* impair*).ab,ti.
9. (intellectual* handicap*).ab,ti.
10. (intellectual*subnormal*).ab,ti.
11. (learning difficult*).ab,ti.
12. (learning deficien*).ab,ti.
13. (learning impair*).ab,ti.
14. (learning retard*).ab,ti.
15. (learning subnormal*).ab,ti.
16. (learning handicap*).ab,ti.
17. (mental* retard*).ab,ti.
18. (mental* deficien*).ab,ti. 19. (mental* handicap*).ab,ti.
20. (mental* disab*).ab,ti.
21. (mental* subnormal*).ab,ti.
22. (intellectual developmental disab*).ab,ti.
23. (intellectual development disorder*).ab,ti.
24. (down* syndrome).ab,ti.
25. (profound* multiple learning disab*).ab,ti.
26. (profound* intellectual* multiple disab*).ab,ti.
27. (pervasive developmental* disorder*).ab,ti.
28. (pervasive developmental* disorder* otherwise specified).ab,ti.
29. (special education* need*).ab,ti.
30. (special education* need* disabilit*).ab,ti.
31. (special need* disabilit*).ab,ti.
32. (developmental* disab*).ab,ti.

33. (developmental* disorder*).ab,ti.
34. (developmental* delay*).ab,ti.
35. (developmental* handicap*).ab,ti.
36. (developmental* retard*).ab,ti.
37. (developmental* subnormal*).ab,ti.
38. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37

Group B

39. MeSH term "PARTICIPATORY ACTION RESEARCH"
40. MeSH term "ACTION RESEARCH"
41. Community participation
42. Stakeholder participation
43. Participatory action research
44. Co-creat*
45. Cocreat*
46. Community-Based Participatory Research
47. CBPR
48. Evidence based co design
49. EBCD
50. Co-produce*
51. Coproduce*
52. Co-design
53. Codesign
54. Participatory design
55. User-center* design
56. Consumer Participa*
57. Client Participa*
58. Emancipatory research
59. Participatory action research
60. Inclusive research
61. Patient participation
62. Citizen science
63. Public engagement
64. Public participant involvement
65. (39 or 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64)
66. 38 and 65
67. Limits publication year 2000-2021

PsychInfo

Group A

Intellectual Disability:

1. MeSH "Intellectual Development",
2. MeSH "Intellectual Development Disorder",
3. MeSH "Learning Disabilities",
4. MeSH "Learning Disorders"
5. (intellectual* disab*).ab,ti.
6. (learning disab*).ab,ti.
7. (intellectual* deficient*).ab,ti.
8. (intellectual* retard*).ab,ti.
9. (intellectual* impair*).ab,ti.
10. (intellectual* handicap*).ab,ti.
11. (intellectual* subnormal*).ab,ti.
12. (learning difficult*).ab,ti.
13. (learning deficient*).ab,ti.
14. (learning impair*).ab,ti.
15. (learning retard*).ab,ti.
16. (learning subnormal*).ab,ti.
17. (learning handicap*).ab,ti.
18. (mental* retard*).ab,ti.
19. (mental* deficient*).ab,ti.
20. (mental* handicap*).ab,ti.
21. (mental* disab*).ab,ti.
22. (mental* subnormal*).ab,ti.
23. (intellectual developmental disab*).ab,ti.
24. (intellectual development disorder*).ab,ti.
25. (down* syndrome).ab,ti.
26. (profound* multiple learning disab*).ab,ti.
27. (profound* intellectual* multiple disab*).ab,ti.
28. (pervasive developmental* disorder*).ab,ti.
29. (pervasive developmental* disorder* otherwise specified).ab,ti.
30. (special education* need*).ab,ti.
31. (special education* need* disabilit*).ab,ti.
32. (special need* disabilit*).ab,ti.
33. (developmental* disab*).ab,ti.
34. (developmental* disorder*).ab,ti.
35. (developmental* delay*).ab,ti.
36. (developmental* handicap*).ab,ti.
37. (developmental* retard*).ab,ti.
38. (developmental* subnormal*).ab,ti.
39. (1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38)

Group B

Inclusive research:

40. MeSH term "CLIENT PARTICIPATION"/

41. MeSH "ACTION RESEARCH"
42. Community participation
43. Stakeholder participation
44. Participatory action research
45. Co-creat*
46. Cocreat*
47. Community-Based Participatory Research
48. CBPR
49. Evidence based co design
50. EBCD
51. Co-product*
52. Coproduc*
53. Co-design
54. Codesign
55. Participatory design
56. User-center* design
57. Patient Participation
58. Collaborat*
59. Consumer Participa*
60. Client Participa*
61. Emancipatory research
62. Participatory action research
63. Inclusive research
64. Patient participation
65. Exp* patient participa*
66. Exp* community partici*
67. Citizen science
68. Public engagement
69. Public participant involvement
70. (40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 OR 66 OR 67 OR 68 OR 69)
71. 39 AND 70
72. Limit to date 2000 to present **BNI**

Group A

1. MeSH term "LEARNING DISABILITIES" 2. MeSH term "DEVELOPMENTAL DISABILITIES"
3. (intellectual* disab*).ab,ti.
4. (learning disab*).ab,ti.
5. (intellectual* deficient*).ab,ti.
6. (intellectual* retard*).ab,ti.

7. (intellectual* impair*).ab,ti.
8. (intellectual* handicap*).ab,ti.
9. (intellectual*subnormal*).ab,ti.
10. (learning difficult*).ab,ti.
11. (learning deficient*).ab,ti.
12. (learning impair*).ab,ti.
13. (learning retard*).ab,ti.
14. (learning subnormal*).ab,ti.
15. (learning handicap*).ab,ti.
16. (mental* retard*).ab,ti.
17. (mental* deficient*).ab,ti.
18. (mental* handicap*).ab,ti.
19. (mental* disab*).ab,ti.
20. (mental* subnormal*).ab,ti.
21. (intellectual developmental disab*).ab,ti.
22. (intellectual development disorder*).ab,ti.
23. (down* syndrome).ab,ti.
24. (profound* multiple learning disab*).ab,ti.
25. (profound* intellectual* multiple disab*).ab,ti.
26. (pervasive developmental* disorder*).ab,ti.
27. (pervasive developmental* disorder* otherwise specified).ab,ti.
28. (special education* need*).ab,ti.
29. (special education* need* disabilit*).ab,ti.
30. (special need* disabilit*).ab,ti.
31. (developmental* disab*).ab,ti.
32. (developmental* disorder*).ab,ti.
33. (developmental* delay*).ab,ti.
34. (developmental* handicap*).ab,ti.
35. (developmental* retard*).ab,ti.
36. (developmental* subnormal*).ab,ti.
37. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36

Group B inclusive research

38. MeSH term "ACTION RESEARCH"
39. Community participation
40. Stakeholder participation
41. Participatory action research
42. Co-creat*
43. Cocreat*
44. Community-Based Participatory Research
45. CBPR
46. Evidence based co design

47. EBCD
48. Co-product*
49. Coproduc*
50. Co-design
51. Codesign
52. Participatory design
53. User-center* design
54. Consumer Participa*
55. Client Participa*
56. Emancipatory research
57. Participatory action research
58. Inclusive research
59. Patient participation
60. Citizen science
61. Public engagement
62. Public participant involvement
63. (38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50
OR
51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62)
64. 37 AND 63
65. 64 limit date 2000-2021

Cochrane Central Register of Controlled Trials (CENTRAL)

Group A

1. MeSH term "Developmental Disabilities",
2. MeSH term "Intellectual Disability",
3. MeSH term "Learning Disabilities"
4. "Intellectual disability*" ab.ti.kw
5. "Intellectual Development Disorder" ab.ti.kw
6. "Mental retard*" ab.ti.kw
7. "Development disorder*" ab.ti.kw
8. "mental deficienc*" ab.ti.kw
9. "Psychosocial Mental Retardation" ab.ti.kw
10. "Persons with Mental Disabilit*" ab.ti.kw
11. "learning disability*" ab.ti.kw
12. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11

Group B

13. "Image*" ab.ti.kw
14. "Mental representation*" ab.ti.kw
15. "mental imag*" ab.ti.kw
16. "imagery assessment" ab.ti.kw
17. "intrusive memories" ab.ti.kw

18. "imag* generat*" ab,ti.kw
19. "imag* maintenance" ab,ti.kw
20. "imag* inspection" ab,ti.kw
21. "imag* transform*" ab,ti.kw
22. "guided imag*" ab,ti.kw
23. "image* rescript*" ab,ti.kw
24. "compassion focused therapy" ab,ti.kw
25. "visualis*" ab,ti.kw
26. "meditation" ab,ti.kw
27. "eye movement desensitization and reprocessing" ab,ti.kw
28. "EMDR" ab,ti.kw
29. "flash forward" ab,ti.kw
30. "flash black" ab,ti.kw
31. "pain manage* AND psychol*" ab,ti.kw
32. "image scanning tasks" ab,ti.kw
33. 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
34. 12 and 33

Published after 1980

ETHoS

Search any word "learning disability" OR "intellectual disability" AND "mental Imagery"

Google Scholar

(intellectual disability OR learning disability) AND (co-production OR inclusive research OR co-design)

Limit to 2000-present

Sort by relevance

Screen first 100 results

Appendix 5: Confirmation of Ethical Approval (Study 3)

Humanities and Social Sciences Research Ethics Committee
Kirby Corner Road
Coventry
CV4 8UW
Tuesday 11 May 2021

Dr Olivia Hewitt

CEDAR

University of Warwick

Coventry

CV4 7AL

Dear Dr Hewitt,

Application Reference: HSSREC 124/20-21

Title: Developing a novel, co-produced, mental imagery intervention with people with mild to moderate intellectual disability

Thank you for submitting your revisions to the Humanities and Social Sciences Research Ethics Committee

(HSSREC) for consideration. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, **full ethical approval for your project is hereby granted, subject to the conditions outlined in Appendix 1.**

Any substantial changes to any aspect of the project will require further review by HSSREC and the PI is required to notify the HSSREC as early as possible should they wish to make any such changes. The HSSREC Secretary should be notified of any minor amendments to the study.

Should issues arise during the course of the project that present risks to the safety and wellbeing of participants, these must be reported to HSSREC. In such an event, recruitment and research activity must be halted until the appropriate actions have been taken, as agreed in consultation with HSSREC.

I would like to take this opportunity to wish you all the best with your study.

Yours sincerely,



Dr Fiona MacCallum

www.warwick.ac.uk

Chair, Humanities and Social Sciences Research
Ethics Committee [Appendix 1](#)

- ✦ Please also be aware that HSSREC grants **ethical approval** for studies. The seeking and obtaining of all other necessary approvals are the responsibility of the Principal/ Chief Investigator.
- ✦ Please ensure that evidence of all necessary local permissions is provided to HSSREC prior to commencing your study.
- ✦ Before conducting your research it is strongly recommended that you complete the on-line [Research Integrity training](#).
- ✦ You must ensure that you are compliant with all necessary data protection legislation. Legal and Compliance guidance can be accessed on their [GDPR information pages](#).
- ✦ In undertaking your study, you are required to comply with the University of Warwick's [Research Code of Practice](#).

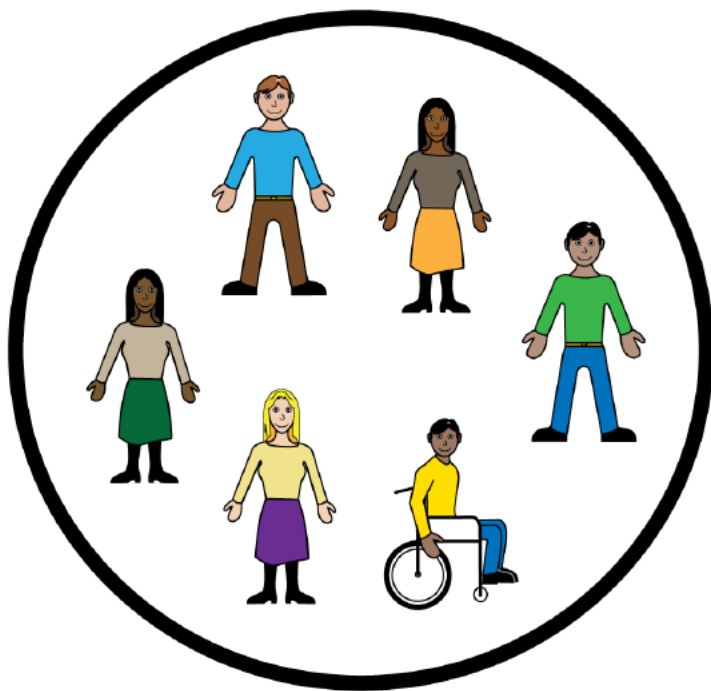
† You are also required to familiarise yourself with the University of Warwick's [Code of Practice for the Investigation of Research Misconduct](#).

† Further advice and support is available from the HSSREC Secretary via HSSREC@warwick.ac.uk.

www.warwick.ac.uk

Appendix 6: Information Sheet and Consent Form (Study 3)

Information about a Research Study



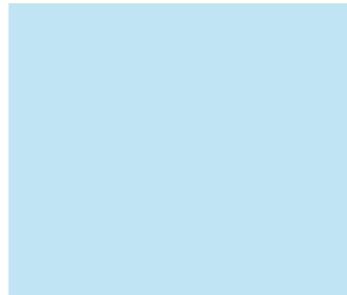
Finding out how people with
learning disabilities think



We are doing a
research study.



Our research is
about finding out
how people with
learning
disabilities think.



Sometimes people think in pictures and sometimes they think in words.



We want to ask you about your thoughts.



Do you want to take part in our research study?



Taking part is your choice.



You do not have to talk to us. You can say no.



If you want, you can talk to your friends, carers, or family about this study.



If you have an advocate, you can talk to them about this study.

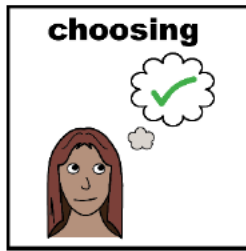


We want to tell you about the study before you make your decision.



If you have any questions, just ask us, and we will answer them. Our contact details are at the end of this leaflet.

What will happen if I take part?



If you say yes to taking part, then a researcher will meet you and talk to you.



The meeting will last about 1 hour.



We will ask you about the kind of thoughts you have.



Sometimes people think in words and sometimes they think in pictures.



We will ask you to think of somewhere nice, like the beach, and tell us what pictures you can see in your head.



We need to record our voices in the interview to play it back later.

Good and bad things about taking part

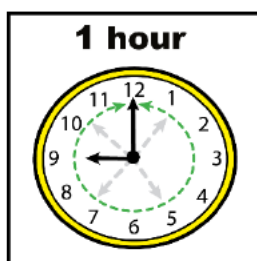


You will help us understand how people with learning disabilities think.



It will take up some of your time.

How long does the study last?

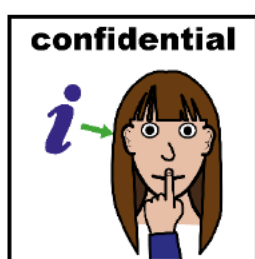


Your interview will last about one hour.

Who will know about me if I take part?



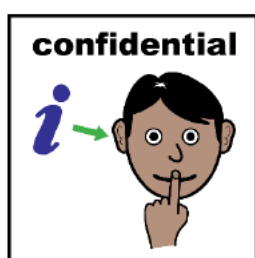
We will know that you said yes, and we will tell some other people. But we will keep your information private.



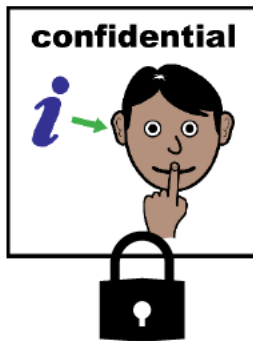
We will keep all the information we have about you confidential. This means it is private. We will not tell other people about you.



We will record your name, address, and telephone number. We will keep this confidential.



To keep information private, we make it anonymous. We will use a special number rather than your name when we write about you. This is to keep your name secret. We might share anonymous information with others. No one will be



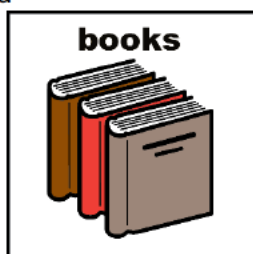
able to tell who you are.



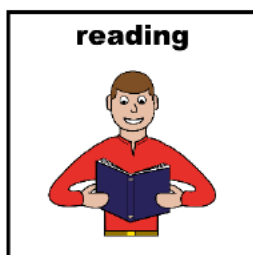
If we think someone is hurting you or someone you know is being hurt, we will have to tell someone else about you. This might be a social worker. We would do this to keep people safe.

What happens at the end of the study?

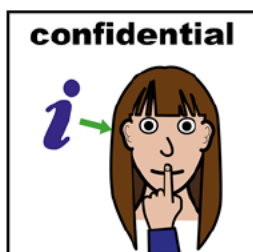
d



We will write about what we have found out and share it. You can have a copy.



This is so other people can read about the study and learn from it.



We will not write your name. You taking part remains confidential

Payment



We will pay you £10 for your interview.

Who has checked this study?



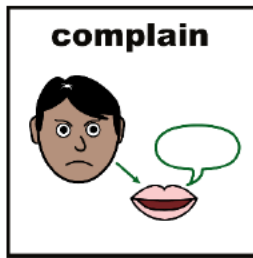
A group of people called an Ethics Committee from the University of Warwick have checked this study.

Who is paying for this study?



The National Institute for Health Research pay for this study. They pay for studies that are about making care better in the NHS.

Complaints



If you are not happy about something, you can ask us to talk to you about it.

Or contact the Head
of Research
Governance
Research & Impact
Services
University House
University of Warwick
Coventry
CV4 8UW
Email:
researchgovernance
@warwick.ac.uk
Tel: 02476 575733



You can talk to
Olivia's supervisor.
His name is Peter
Langdon.
His phone number is
[REDACTED]
His email is:
[REDACTED]
His address is
[REDACTED]

Who is doing this study?



Olivia Hewitt is doing the study. She is a PhD student. Olivia also works in the NHS as a clinical psychologist

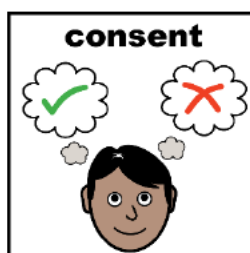


You can contact Olivia by calling [redacted] or emailing her: [redacted] or write to her at [redacted]

What happens next?



You choose if you want to take part in our study.



This is called getting your consent. You choose yes or no.



If you want to take part, we will ask you to sign a consent form. This form is at the end of this leaflet.



If you do not want to take part in our study. This is ok. It is your choice.



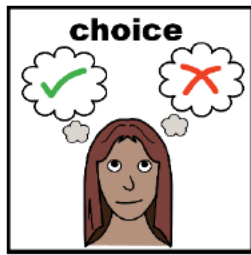
Take some time to make a choice. Talk to others, like a friend, carer, or family member.



If you have any questions, ask them.



When you make your decision, tell us.



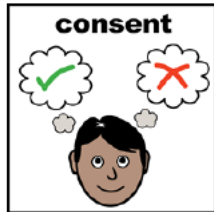
If you decide to take part, you can change your mind later. You do not have to give us a reason. It's your choice.

Some images are copyright © LYPFT



CONSENT FORM

Unique Participant Identification
Number



This is a consent form. You should complete this form if you want to be in our study.



You need to read each part and tick to show you agree. Then sign your name. We will read this with you.

Please tick

Yes No

S

I understand the information about the study Finding out how people with learning disabilities think

☐	☐
--------------------------	--------------------------

Yes No

S

I have spoken to the research team, and asked questions, if I wanted. They answered any questions I asked.

☐	☐
--------------------------	--------------------------

Yes No

S

I understand that taking part is my choice. I can change my mind in the future and say that I no longer want to be in the study. I do not have to tell the researchers why.

☐	☐
--------------------------	--------------------------

Yes No
S

I understand that if I stop taking part in this study in the future, it will not affect my care or treatment.

--	--

Yes No
S

I understand that a researcher will meet me to talk about my thoughts. They will record the interview.

--	--

Yes No
S

I understand that the information collected about me will be made anonymous. This anonymous data may be shared with other researchers. I agree to this.

--	--

Ye No
s

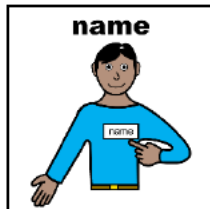
I understand that if I change my mind in the future and no longer want to be in the study, the researchers will ask to keep my contact details and my interview data. I can say no if I want.

--	--

Ye No
s

I agree to be in the study.

--	--



What is your name?



What is your phone number?



What is your address?



Your signature



Today's date

Name of the Person
taking consent:

Signature:

Date:

Some images are copyright ©
LYPFT

Appendix 7: Confirmation of REC Approval (Study 6)

WoSRES

West of Scotland Research Ethics Service



Dr Olivia Hewitt
Clinical Psychologist/ PhD student
Berkshire Healthcare NHS Foundation Trust
Earley House
University of Reading
Whiteknights Road, Reading, Berkshire
RG6 6BZ

West of Scotland REC 3

West of Scotland Research Ethics
Service
Ground Floor Ward 11
Dykebar Hospital
Grahamston Road
Paisley PA2 7DE

Date 07 March 2024
Direct line [REDACTED]
E-mail [REDACTED]

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Dear Dr Hewitt,

Study title: Testing a co-designed mental imagery anxiety intervention for people with mild to moderate intellectual disabilities (Co-MAID)
REC reference: 24/WS/0022
IRAS project ID: 334578

Thank you for your letter of 29 February 2024, responding to the Research Ethics Committee's

(REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: [Research registration and research project identifiers](#)).

Where a deferral is agreed we expect the sponsor to publish a [minimal record](#) on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, [a minimum research summary](#) will still be published in [the research summaries database](#). At the end of the deferral period, we will publish the [full research summary](#).

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: [Research summaries - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/researchsummaries)

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: [Reporting requirements](#)

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at [Managing your approval - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/managingyourapproval)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [recruitment flyer]	1.0	20 December 2023
Covering letter on headed paper [cover letter]		01 February 2024
GP/consultant information sheets or letters [letter to GP]	1.0	20 December 2023
Interview schedules or topic guides for participants [Participant semi structured interview schedule]	1.0	20 December 2023
Interview schedules or topic guides for participants [supporter semi structured interview schedule]	1.0	20 December 2023
IRAS Application Form [IRAS_Form_01022024]		01 February 2024
Letter from funder [letter from funder]		09 January 2020
Non-validated questionnaire [qualitative session by session feedback]	1.0	20 December 2023
Participant information sheet (PIS) [participant information sheet and consent form]	1.1	29 February 2024
Participant information sheet (PIS) [supporter information sheet and consent form]	1.1	29 February 2024
Referee's report or other scientific critique report [NIHR review]		
Referee's report or other scientific critique report [O Hewitt annual review]		21 September 2021
Referee's report or other scientific critique report [O hewitt upgrade report]		06 December 2021
Research protocol or project proposal [Co-MAID protocol]	1.1	29 February 2024
Response to Request for Further Information [Cover letter]		29 February 2024
Summary CV for Chief Investigator (CI) [O Hewitt CV]		20 December 2023
Summary CV for student [CV O Hewitt]		20 December 2023
Summary CV for supervisor (student research) [CV P E Langdon]		
Summary CV for supervisor (student research) [CV M Larkin]		
Summary CV for supervisor (student research) [CV C Steel]		20 December 2023
Summary, synopsis or diagram (flowchart) of protocol in non technical language [participant flow diagram]		
Validated questionnaire [Glasgow anxiety scale]		
Validated questionnaire [psychological therapy outcome scale-ID]		
Validated questionnaire [psychological therapies outcome scale proxy]		
Validated questionnaire [adapted VVIQ]		
Validated questionnaire [Adapted GAD and PHQ]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: [Quality assurance - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/quality-assurance)

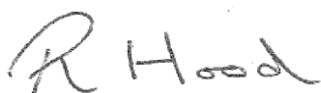
HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: [Learning - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/learning)

IRAS project ID: 334578 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,



On behalf of

Ms Karen McIntyre Chair

Enclosures:

**[After ethical review guidance for sponsors and investigators –
Non CTIMP Standard Conditions of Approval](#)**

Copy to:

Ms Emma Donaldson, Berkshire Healthcare NHS Foundation
Trust

Appendix 8: Intervention Refinements (Study 5)

Modification number	Who suggested modification?	What is to be modified?	Nature of the content modification	Reasons for modifying	Agreed / declined	Why agreed/ declined
1	OH	Print person's workbook single sided	Change in materials	Easier to remove pages to complete homework tasks	Agreed - done 09/01/2025	
2	OH	Add session by session qualitative feedback form to materials for each session in person's workbook	Change in materials	Prevent this being forgotten	Agreed – done 09/01/2025	
3	OH	Add adapted safe place and kind helper exercises written out in person's workbook	Change in materials	Access to resources – allows person to refer back to exercises in written format after intervention	Agreed - Done 09/01/2025	
4	OH, SUP01	Prompt (in therapist manual and person's workbook) to check that person can open and access audio files of kind helper and safe place exercise	Change in materials	Access to resources	Agreed - Done in person's workbook 09/01/2025	
5	OH	Clarify that mid intervention standardised measures should be administered after session 5 (not	Change in materials	Improve consistency	Declined.	Already clearly stated in therapist manual

		before) in therapist's manual				
6	OH	Supporter CRF need to add yoked participant ID and initials to form	Change in materials		Agreed – done 15/05/2024	
7	OH	Participant CRF and supporter CRF add extra boxes for ID number	Change in materials		Agreed – done 15/05/2024	
8	OH	Check consistency of language around calm/ safe place in person's workbook, intervention protocol and therapist's manual	Change in materials	Improve accessibility	Agreed - Done 09/01/2025 changed to 'calm place'	
9	OH	Check consistency of language around kind helper in person's workbook, intervention protocol and therapist's manual	Change in materials	Improve accessibility	Accepted 22/1/2025	Changed to kind helper
10	OH	Session 6 learning to move our attention page 59 has a lot of text on it – would this be better placed in therapist manual?	Change in materials	Improve accessibility	Declined –	reviewed and this level of detail is in line with the other mental imagery components. Having this detail allows people to resist the exercise post intervention.
11	OH	Need to ensure we retain a copy of 'what was helpful in therapy worksheet' page 71 as only copy in person's	Change in materials	Tailoring/tweaking/ refining	Agreed - Done 09/01/2025 Added prompt to	

		handbook. Could add another copy for therapist to take away or continue to take photo and replicate at end of intervention			therapist's manual	
12	SUP01, PPT02, SUP03	Change the wording on information sheet and consent from 'interview' to 'chat'	Tailoring/tweaking/refining	Improve accessibility	Declined –	this would require ethics amendment so could change for feasibility study?
13	OH	I have tended to hold on to the person's workbook between sessions and then hand over at the end of intervention. Should I have a spare copy which the person can keep between sessions?	Change in materials	Improving accessibility	Agreed done 15/01/2025	Added section to therapist's manual so participant can hold on to a copy of workbook between sessions of they want to.
14	OH	Psychoeducation materials re anxiety	Tailoring/tweaking/refining	Information presented is too complex	Declined 21/1/2025	In future could have a more and a less complex version of these materials – perhaps using different images (easy on the eye/ photosymbol) to reflect different levels of ability
15	OH, PPT01	Add multi-sensory exercise to develop safe place imagery through drawing/ collage etc	Change in materials	Improve accessibility	Done 09/01/2025	Added a specific prompt to therapist's manual

16	OH	Have standardised assessments in more accessible online format (Microsoft forms) as well as paper options.	Change in materials	Access to resources	Declined	– to add as a change for feasibility study
17	OH, ALZ	Discard VVIQ as not sensitive to change and long and unwieldy measure. Could replace with Negative Mental Imagery Questionnaire (MIQ-N) or 3/4 separate visual analogue scales to capture change relating to different mental imagery components?	Change in materials	substituting	Agreed	Changed to MIQ-ID
18	OH, PPT02	Should end of intervention interview be conducted by therapist or RA. Participants have found it hard to engage with someone new, especially if not familiar with intervention.	Contextual change	Improve accessibility	Declined 15/01/2025–	Ned to ensure Research Assistant for future trial has experience working with people with intellectual disabilities
19	OH, PPT02	Should a supporter be mandatory?	Adding elements	Improve accessibility	Decline 21/01/2025	Not a mandatory part of intervention but it is highly recommended, and a core part of intervention as reflected in our logic model
20	OH	Review inclusion / exclusion criteria.	Adding elements	Reduce drop out	Declined 21/1/2025	To revisit for feasibility trial

		Currently very broad. Should we exclude PTSD? Additional difficulties with engagement due to sensory issues (hearing) and complex physical health issues (PPT03)				
21	PPT02	Assessment needs to ensure any physical health issues that may hinder engagement e.g. hearing issues are identified and addressed before starting the intervention	contextual	Physical capability	Agreed 21/1/2025	Need to undertake comprehensive assessment to understand sensory impairments and be able to put in place strategies to support them accessing intervention. Where participant has sensory impairments that precludes them accessing materials, this would be a barrier to this intervention.
22	OH, PPT01	Completing daily mood recordings seen as positive experience and high compliance. Could it be part of the intervention? To be added to logic model? Implications for feasibility trial when	Change in materials		Accepted 21/1/2025	Change to intervention – rationale changed. Participants find this daily measure helpful and is part of helping people to understand how changing their mental imagery can impact their mood. Added to logic model

		people are not required to do this going forward?				
23	OH	Engagement with between session tasks is variable. Can we use apps etc to help practice skills?	Change in materials	Improving accessibility	Accepted 21/1/2025	Apps – Olivia to look at CFT apps and see which might be useful
24	OH	Make breathing exercise available in different formats e.g. audio/ app? Some clients able to access digital information.	Change in materials	Improving accessibility	Accepted 21/1/2015	OH to look at CFT apps and see which might be useful
25	DL	Change order of mental imagery components. Start with switching attention/ grounding, then safe place, then kind helper	In line with CFT theory	Reordering of intervention segments	Accepted 22/1/2025	In line with CFT theory and should help participants to access session content
26	DL	Develop sensory materials (soothing touch and smell) at start of intervention (session 1 or 2) and then use at start of each session with client	In line with CFT theory	Reordering of intervention segments	Agreed 15/01/2025	In line with CFT theory and should help participants to access session content
27	DL	Add grounding and breathing to start of every intervention session.	In line with CFT theory	Reordering of intervention segments	Agreed 15/01/2025	In line with CFT theory and additional opportunity to practice new skills
28	SUP01	Could set joint homework with	Content/ implementation	Adding elements	Agreed 21/1/2025	Added to strategies for improving homework

		participant and supporter working on something together				uptake (developed with stakeholder group) to therapist's manual
29	SUP01	Provide exercises (safe place/ kind helper) and blueprint as audio files	Change in materials	Improve accessibility	Declined –	this is already part of protocol
30	SUP01	Would it be helpful if the app sent daily recordings and the attached comments as well to contextualise the scores	Change in materials	Adding elements	Declined – OH 09/01/2025	not possible on the Daylio app and not necessary for SCED
31	PPT02	Asthma made breathing exercises hard to engage with – could have alternative strategies?	contextual	Physical capability	Accepted 21/1/2025	Alternatives (e.g. progressive muscle relaxation) are acceptable as long as they have the same aim/ goal
32	PPT02	Didn't find Rubix cube helpful but does enjoy playing games on phone – could try to incorporate things the person already enjoys or uses.	Changes in materials	Improve accessibility	Agreed - Done 09/01/2025	prompt added to therapist's manual
33	NHS service lead (SW)	Summary document for clinical service would be helpful to include engagement/ helpful and unhelpful strategies and recommendations for the future. Template document proposed from service	Change in materials	Improve communication with clinical services	Accepted 21/1/2025	To complete local documents in line with NHS services. Add to therapist manual

34	OH	Ensure all mention of SUP standardised measures in therapist manual and protocol have been removed	Change in materials		Declined 21/1/2025	Proxy PTOS should be collected at all time points. Feasibility trial will use proxy ratings as well as respondent measures
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Appendix 9: Excerpts from Reflexive Log

16/07/2021

Teams call yesterday with SJF from Birmingham – had some useful things for us to think about re PPI and stakeholder groups:

- Frequency and length of meeting – may be that every other month for 2 hours is more productive.
- Think about location of group and how comfortable people will feel
- Need to provide refreshments and ask people what they want
- Need to have clear purpose of each meeting
- Also need to have overall purpose of the group (each one) outlined.
- Need clear boundaries around my role and good liaison with CTPLD – might need to email Anne to discuss.
- Group rules – need refreshing each session
- Need a loose structure for each group session – recap, refresh group rules, work for the session and then wrap up and debrief and look to next session
- Need good lone worker policy in place
- Be bold and creative – can do things differently.
- Stakeholder group – how do they wish to position themselves?

Need to make sure I pay attention to both of these groups – different challenges for each...

21/07/2021

Just reading some literature around d co-production. One of the tasks will be around me having a different role now for both groups – not as a colleague or therapist but as a co-researcher. How will I negotiate this? What tools will help me (this log, supervision etc). But also need to acknowledge that part of why some people have joined the groups is because of our pre-existing relationship. How to negotiate any changes? What challenges can I anticipate? And what about pre-existing relationships will be helpful? Will new people feel excluded? How to build these relationships and be clear about current boundaries. Something I've been thinking lots about especially re Agatha's death

16/8/2021

Made good progress with the study and have first co production group today, have done as much preparation as I can but need to trust in the process, I think. Hard to know what it will be like especially online – I'd feel more confident with people in real life, I think. Wonder how technology will work and whether people will be able to access stuff easily...also worried about not having a cohesive sense of the group as we're not in the same physical space. Wonder if there's anything new can do to help with this. Might ask the group if they have ideas.

17/8/2021

Group went well overall – a few mistakes with recording not starting at the right time and I think we forgot Marie. Was hard work getting the group to interact over zoom but overall it worked ok, Having a smaller group of 4 people with ID worked well as able to spend time directing questions to each of them. Got some really useful thoughts and amendments. Just done the

easy read minutes to be sent out – will need an easy read agenda for next time. Overall, really pleased with this. Does make me think that I will need to do individual interviews face to face if at all possible...

23/8/2021

Stakeholder group went really well – so pleased with their thoughts and inputs. Really felt so valuable having extra heads thinking about the project and how best to do bits of it. Also so clear how much experience and expertise they have in working with people with ID. Everyone seemed to get on well and was able to speak. Planning the next one for end of September which might be a bit ambitious but I'm hopeful I might have done some interviews by then so can get some feedback from them. Also spoke with Mandy last week which was good and I can do some face to face interviews which will be much better than online I think. Just need to finalise the format and the use of images – still a bit confused so need to work on the theoretical rationale for this, might get hold of Zoe Boden and see if she has time for a quick chat about this...all feels like it's moving forward in a good way...

31/08/2021

Discussion with Michael

Rationale for imagery methodology – people might have really good imagery which we might not capture because they can't convey this with their limited verbal skills. Could be – which is why we are adding nonverbal methodology i.e. creating images.

Our interest is in the relationship people have with imagery which can be communicated verbally/ through images/ through nonverbal cues and energy and animation. Will be able to use these skills as interviewer and clinical psychologist to identify and explore this. No sure what a better way of doing this could be! Could look at performance and drama psychotherapy but not sure how we could analyse and make sense of this.

Look at project with autism and collage - Birmingham Ridout, S. (2014). More than picture-making: reflecting on collage as a narrative tool for opening discourse on the involvement of autistics in autism research. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(3).

Thoughts about interviews – pilot a couple and then discuss with Michael.

Capture my thoughts and reflections in voice note format after interview (these can be transcribed using Otter and useful bits highlighted)

Could do 2 interviews – one focus on making images and one on verbal stuff – will take materials for all bits and see what people are most interested in doing with me on the day. Flexibility.

8/9/2021

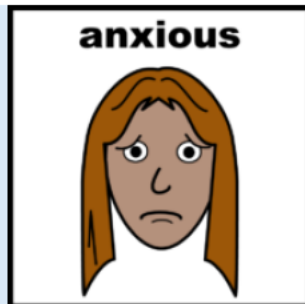
Doing first interview today to pilot. Feeling well prepared and looking forward to it. Must make notes/ voice notes immediately afterwards to capture my thoughts. Will probably use Dictaphone/ iphone voice memo. Feels like things are moving forward well at this stage – need to do some reading on data analysis with people with ID and how to help with this. Might look up Melanie Nind and Jam Walmsley stuff...

Just recording a voice note after the interview with Claire, which was the first interview went really well, she was very able to engage and describe mental imagery really vividly in all different senses as well. She seems to enjoy doing the interview and her collage was really quite limited. But interestingly, it was very multisensory. She I think she understood everything I was asking her to do, I ended up doing the bedroom image exercise, which seemed fine, I just gave her choice and that was the one she wanted to do. I think it's gonna be interesting distinguishing memory and mental imagery. So we did the bedroom image we did the collage, and then we finished off by doing the VVIQ, rather than the guided imagery on the beach because we've already talked about the beach and she's kind of been able to do that absolutely fine and seem very happy. So there we are, and on to the next one.

Appendix 10: Draft Easy Read Document to Summarise Project

The Co-MAID research project

What was this project about?



Our project was about making an intervention to help people with anxiety.



We want to help people change their mental images (pictures in their heads), so they feel less anxious.

What did we do?



First, we did some interviews to see if people with intellectual disabilities can have mental images.



People with intellectual disabilities were good at this! They made clear, detailed mental images.



We found out what helps us to have good mental images:

- having instructions we understand
- asking us questions to help develop our images.



We held a big workshop to bring lots of people together. We thought together about what to include in our anxiety intervention.



Our intervention is called Co-MAID. This stands for a Co-Designed Mental Imagery intervention for People with mild to moderate Intellectual Disabilities.



We had lots of ideas to make Co-MAID easier for people with intellectual disabilities to understand.

Testing out Co-MAID



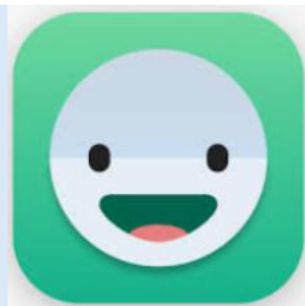
Olivia tried out Co-MAID with 6 people in the NHS



Most people enjoyed the sessions. They felt more relaxed afterwards



They said mental images were easy to change.



They liked using apps to practice breathing exercises and record how they feel every day.

What did we learn?



What have we learnt from our research?



- Doing research is fun! People with learning disabilities enjoyed doing research.

better care



- We can help some people who feel anxious to feel better by changing their mental images.

What is next?

group



Now we have money to try out the Co-MAID intervention with 40 people in the NHS.

working together



People with learning disabilities and other researchers will help Olivia to do this.

