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The value of 'third-wave' therapies in Intellectual Disability services
service user experiences of adapted Dialectical Behaviour Therapy

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The value of 'third-wave' therapies in Intellectual Disability services: service user experiences of adapted Dialectical Behaviour Therapy.

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Dedication

I dedicate this thesis to the memory of my incredible Grandad Eryl; my all-time biggest

supporter and greatest inspiration, who, sadly, did not quite see me make it to the end.

Nobody would have been prouder than you.

TABLE OF CONTENTS

Thesis Abstract

This thesis explores the value of utilising 'third-wave' psychological therapies within intellectual disability (ID) services.

The first chapter consists of a systematic literature review and meta-analysis, which explores the efficacy of using mindfulness-based interventions (MBIs) to reduce stress among both professional and parental caregivers of individuals with intellectual and/or developmental disabilities (IDD). A systematic review returned 2,346 papers, of which, 14 studies met the inclusion criteria (six including professional caregivers, and eight including parental caregivers). Consistent with previous reviews, the meta-analyses identified a small to moderate effect size of MBIs in reducing stress among parental caregivers. No effect was found for professional caregivers; study findings were mixed, although did highlight a possible dose-response relationship. Further research is necessary in order to develop the evidence base, however preliminary findings show promise for the use of MBIs for caregivers within ID services.

The second chapter presents findings from an empirical study, which adopted a qualitative approach to explore service users' experiences of adapted Dialectical Behaviour Therapy (DBT) in community ID services. The principles of interpretative phenomenological analysis (IPA) guided the analysis of semi-structured interviews, conducted with six participants. Four super-ordinate themes emerged from the data; representing the concurrent challenging and rewarding nature of participants' therapeutic journeys. Implications for clinical practice and recommendations for future research are discussed.

The third chapter considers theoretical and clinical implications that arose from the first two papers and highlights a significant paucity of research generally within the field of ID. The paper concludes with personal reflections of the research process.

Chapter 1

Meta-analysis and Systemic Literature Review

The efficacy of mindfulness-based interventions in reducing stress among caregivers of individuals with intellectual disabilities: A meta-analysis and systematic review.

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Abstract

Caring for individuals with intellectual and/or developmental disabilities (IDD) is associated with elevated levels of stress, which can lead to burnout and poor-quality care. This systematic review and meta-analysis reviews evidence on the efficacy of mindfulness-based interventions (MBIs) for reducing stress among professional and parental caregivers of individuals with IDD. A systematic review of the literature returned 2,346 papers. Baseline and outcome data were extracted for 14 studies (six including professional caregivers and eight including parental caregivers) which met the inclusion criteria, and effect sizes were calculated and entered into the meta-analyses. Consistent with previous reviews, the meta-analyses identified a small to moderate effect size of MBIs in reducing stress among parental caregivers. No effect was found among professional caregivers; study findings were mixed, although did highlight a possible dose-response relationship. The current review supports that MBIs may be effective in reducing stress among parental caregivers, at least in the short term. Further research is warranted in order to further develop the evidence base for MBIs among caregivers of individuals with IDD. Limitations of the current review and recommendations for future research are discussed.

Keywords: Mindfulness, caregivers, developmental disability, intellectual disability, psychological stress.

Background

Whilst caring for individuals with intellectual and/or developmental disabilities (IDD) has been associated with positive factors such as personal growth (Ellingsen et al. 2014), it has also been consistently associated with elevated levels of stress and compromised psychological well-being. This includes both parental and professional caregivers; with significant levels of stress indicated in over 90% of parents (Nikmat et al, 2008) and one third of professionals (Robertson et al., 2005). A range of potential stress-inducing factors have been highlighted, including: the presence of behaviours that challenge (Korsitas et al., 2010); adaptive functioning impairments (Estes et al., 2009); communication difficulties (Baker et al., 2003); large workloads and long hours/shift working (White et al., 2006); insufficient training and support (Rose et al., 2010); and stigma associated with IDD (Sharpley et al., 1997). Such stressors place caregivers at real risk of burnout and psychological distress, which are also found in high levels among parental (Estes et al., 2013; Lach et al., 2009) and professional caregivers (Gray-Stanley, 2009). This often precipitates further negative outcomes such as increased marital conflict and divorce among parents (Namkung et al., 2015) and lower job satisfaction, reduced performance, higher rates of absenteeism and increased turnover among professionals (Crawford et al., 2010; Schuengel et al. 2010).

Moreover, caregiver stress also has significant implications for the individuals being cared for. Stressed caregivers are more likely to develop negative attitudes towards care recipients (Ó Donnchadha, 2018), engage in increased negative interactions with, or avoid them (Jahoda et al., 2013) and are less likely to effectively manage behaviours that challenge (Rose et al., 2010). Thus, highlighting the potential for stress to impede one's caregiving ability and ultimately cultivate poor quality care or even abusive practice (Francis, 2013; Rose et al., 1998; White et al., 2003). It has been postulated that such poor-quality care can further provoke behaviours that challenge among care recipients, which consequently further exacerbates

caregiver stress; thereby suggesting the existence of a transactional relationship between the two (Neece, Green & Baker, 2012).

With the detrimental effects of caregiver stress clearly documented, it is crucial that evidence-based interventions are developed that target stress among this population to protect caregiver and recipient wellbeing, and prevent poor practice and/or abusive conditions.

Existing interventions

To date, interventions for parents have often targeted stress indirectly through behavioural parent training programmes, which aim to help parents develop strategies to modify their child's behaviour (Lindo et al., 2016; Solomon et al., 2007). However, such approaches have been criticised for neglecting to address stressors aside from those directly related to the child with IDD (Jones et al., 2017). Alternative interventions, for both parents and professionals, have targeted stress directly through Cognitive Behavioural Therapy (CBT) approaches which focus on cognitive restructuring through modification of dysfunctional cognitions (Hastings & Beck, 2004; Singer, Ethridge & Aldana, 2007; Gardner et al., 2005; Kushlick, Trower & Dagnan, 1997). Emphasis is placed on changing cognitions associated with difficult emotions and situations, based on the assumption that individuals are more likely to engage in effective coping strategies if they interpret stress in an alternative way. However, in reality, this may not always be possible for caregivers of individuals with IDD, as many of the inherent daily challenges cannot be easily modified, and often transcend maladaptive cognitions (Noone & Hastings, 2010; MacDonald et al., 2010; Robertson et al., 2005). In fact, studies have highlighted how further distress can actually arise from failed attempts to problem solve, or strategies used to supress, reduce or avoid distressing experiences (Devereux et al., 2009; MacDonald et al., 2010). Caregivers of individuals with IDD may therefore benefit from

alternative approaches which are less problem focused and instead offer alternative ways of responding to stressors and foster an improved general resilience (Jones et al., 2017).

Mindfulness-Based Interventions (MBIs)

Mindfulness has been defined as purposefully focusing one's attention on the present moment, in a non-judgemental and accepting manner (Kabat-Zinn, 1990). Mindfulness-based interventions (MBIs) refer to a collection of 'third-wave' therapies which incorporate mindfulness meditation principles and practices including: Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1990), Mindfulness-Based Cognitive Therapy (MBCT; Teasdale et al., 1995; 2000) and Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999). In contrast to CBT, MBIs focus on accepting difficult experiences such as stress, rather than attempting to modify, avoid or remove them (Hayes, 1987). Enhanced awareness of the present moment enables one to consider a wider range of response options and cultivate more effective ways of managing challenging situations. Research has shown MBIs to be effective in reducing stress and improving wellbeing among a variety of populations and for numerous difficulties including: chronic stress (Chiesa & Serretti, 2009); chronic pain (Lovas et al., 2017); workplace stress (Flaxman et al., 2013); depression (Hoffman et al., 2010); and anxiety (Vollestad et al., 2012). Furthermore, research has demonstrated positive effects of MBIs among caregivers of a number of populations including, individuals with cancer (Birnie et al., 2010), Parkinson's disease (Cash et al., 2016) and dementia (Kor et al., 2018). Given the focus on acceptance rather than change, MBIs may be particularly beneficial for caregivers of individuals with IDD, given that in reality, many of their daily challenges cannot be easily modified.

Despite a general reluctance to adopt new therapies within the field of IDD (Hastings & Manikam, 2013) there is now a growing literature for the application of MBIs among this

population. Although the research remains in its infancy, preliminary findings suggest MBIs have beneficial effects among individuals with IDD and their caregivers. Findings have demonstrated that individuals with IDD can successfully engage with MBIs leading to improvements in aggression and sexual arousal (Chapman et al., 2013). For caregivers, research has demonstrated positive effects of MBIs such as reduced stress (Cachia et al., 2016; Singh et al., 2016a), improved global health outcomes (Ferrailoi & Harris, 2013) and improved psychological wellbeing (McConachie et al., 2014). Findings have also demonstrated that mindful caregiving exerts positive effects for care recipients, such as improved behaviour (Neece 2014) and reductions in the use of physical restraint (Singh et a., 2016b).

Four recent reviews have been conducted which have aimed to synthesise the literature on the use of MBIs for caregivers of individuals with IDD. Hwang and Kearney (2014) reviewed seven papers investigating the effectiveness of MBIs in reducing stress and psychological distress among both parental and professional caregivers of individuals with IDD. For parents, direct effects were highlighted such as improved interaction with children, reductions in stress and increased happiness. Conversely findings for professionals were mixed; improvements were evident in relation to staff satisfaction with work and psychological well-being, however perceived work stressors were observed to increase. Findings also revealed crossover effects for care recipients, supporting the existence of a transactional relationship. Leoni et al. (2016) reviewed the literature specifically for the use of ACT interventions among professional caregivers, and demonstrated positive effects in promoting psychological wellbeing and reducing stress. Rayan and Ahmad (2017) conducted a systematic review of the literature for the use of MBIs among parents of children with IDD; critical appraisal of eight papers revealed promising support for the efficacy of MBIs in reducing stress and psychological distress among parents. Most recently, Ó Donnchadha (2018) extended the work of Leoni et al. (2016) by reviewing the effects of MBIs on stress and psychological

distress outcomes among professional caregivers, utilising a broader conceptualisation of MBIs; findings revealed a positive impact on psychological distress but mixed findings in relation to stress. Whilst the existing reviews provide preliminary support for the efficacy of MBIs in reducing stress and psychological distress among caregivers of individuals with IDD, no previous review has utilised meta-analysis as a method of synthesising the literature and estimating an average effect size for MBIs in reducing stress among caregivers.

Aims

For the purpose of this review, caregivers were divided into two separate groups; parents and professionals. This was due to the fundamental nature and subsequent experience of the roles being inherently different. The aim of the current study was thus two-fold: to evaluate the effectiveness of MBIs in reducing stress among a) professional caregivers and b) parental caregivers. The aims were addressed by conducting a systematic review and meta-analyses to generate overall effect sizes for reducing stress among professional and parental caregivers.

Method

Search strategy

Systematic searches were conducted in November 2017 across two electronic databases (Web of Science and ProQuest). Databases were searched using various combinations of the following Boolean terms: '(mindfulness OR acceptance and commitment therapy OR reflective practice) AND (parent* or caregiver*) AND (intellectual disabilit* OR learning disabilit* OR developmental disabilit*)', and '(mindfulness OR acceptance OR psychological resilience) AND (support staff OR caregiver* OR parent OR professional*) AND (intellectual disabilit* OR learning disabilit* OR developmental dis*)', and '(mindfulness OR acceptance OR reflective practice) AND (intellectual disabilit* OR learning disabilit* OR developmental

disorder)'[1]. Searches were restricted to include only English language papers. No restriction was placed on the date of publication. Ancestral searches were also conducted on the identified papers.

Eligibility criteria

For studies to be included in the analysis they needed to meet the following inclusion criteria:

- Studies needed to have evaluated the effectiveness of a MBI among individuals providing care for individuals with IDD.

- A MBI must have been implemented. This definition included: MBCT, MBSR, ACT. Interventions designed by researchers/authors were included if there was evidence it was based on any of these approaches.

- Participants must have been either a professional caregiver working within an IDD setting, or a full-time parental caregiver for an individual with IDD.

- Studies needed to state that the individuals being cared for had IDD, ascertained either by a formal diagnosis, caregiver report or stipulated in the study criteria.

- No restriction was placed on the age of the participants or care recipients.

- Studies were required to use an experimental, quantitative design (e.g. randomised controlled trial (RCT); non-randomised controlled trial; uncontrolled trials). All single-case and multiple baseline experimental designs were excluded, as were all qualitative studies and theoretical papers. Unpublished dissertations and theses were not included.

- Studies were required to have collected pre- and post- intervention data, using standardised measures, of either stress or burnout (e.g. the Perceived Stress Scale (PSS); Cohen et al., 1983, or the Maslach Burnout Inventory (MBI); Maslach et al., 1996).

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[1] See supplementary information for full list of searches.

Study selection

The titles and abstracts of all the papers identified within the searches were screened by the first author; all papers considered not relevant were excluded. All remaining papers were read in full and assessed for eligibility (see figure 1 for diagrammatic representation of the selection process).

Data extraction

Data was extracted from each paper by the first author. Data was obtained for: participant demographics, intervention, control conditions (where applicable) and outcome measures. The pre- and post- means and standard deviations relating to the standardised measures of stress or burnout were extracted; where measures of both were available, only those relating to stress were obtained. Given that few studies provided follow-up data (of which the time period was variable), only the data relating to outcomes assessed immediately post-intervention was utilised. In instances where a second analysis was completed with a sub group of the sample (i.e. only participants considered clinically distressed at baseline), only the data from the initial analysis was used. Where the raw data was not reported in the published article, this information was requested from the corresponding author by e-mail (two reminders were sent to authors who did not respond).

Assessment of study quality

The methodological quality of each of the included studies was assessed utilising the criteria proposed by Reichow, Volkmar & Cicchetti (2008) in their Evaluative Method for Determining Evidence-Based Practice (EMDEBP). This method, designed specifically for use within autism research, has demonstrated sound psychometric properties (Reichow, 2011) and has been widely used within IDD research to distinguish between varying levels of methodological rigour (Chapman et al., 2013; McNair, Woodrow & Hare, 2016; Wendt & Miller, 2012). In

light of this, and the fact that all care recipients presented with IDD, these criteria were considered appropriate for use in the current review. In accordance with this method, each of the included studies were appraised against Reichow's (2011) primary and secondary indicators of research methodology. For each study, primary quality indicators (e.g. participant characteristics, independent variable, control condition) were appraised as either high, acceptable or unacceptable quality, and secondary quality indicators (e.g. random assignment, treatment fidelity) were rated dichotomously as either containing or not containing evidence of each indicator. Primary and secondary indicator ratings were then synthesised to provide an overall quality rating for each study. Studies were awarded one of three quality ratings; strong, adequate or weak.

Data analysis

All statistical analyses were conducted in the statistical software environment R v.3.4.3 (R Core Team, 2017) using the meta-analysis package, Metafor (Viechtbauer, 2010). The effect size for each study was then calculated from the extracted mean and standard deviation. In instances where the mean was available but standard deviation could not be obtained, the standard error was computed and transformed into the standard deviation using the following equation:

$$SD = \frac{SE}{\sqrt{\frac{1}{N_E} + \frac{1}{N_C}}}$$ (Higgins & Deeks, 2011)

The effect size for each study was calculated using the 'escalc()'[2] function in R. Specifically, the standardised mean change was derived for each study by computing the mean difference between pre- and post- scores, divided by the baseline standard deviation (Becker, 1988; Morris, 2000). The final effect size used for each study was the difference between the effect sizes of the treatment and control groups; in the absence of a control group, the effect size from

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[2] R code for all analyses run can be found in the supplementary information.

pre- to post-test was calculated relative to zero (Morris, 2008; Viechtbauer, 2010). Negative values indicated an improvement in scores (reduction of stress) from pre- to post-intervention. Effect sizes were interpreted in accordance with Cohen's (1988; 1992) guidelines as either, small (0.2), moderate (0.5) or large (0.8). To enable the standard error to be calculated for the effect sizes, the pre- and post-test correlation coefficient must be extracted for the outcome measures within each study. This information was not reported in any of the included studies, so instead, we aimed to extract the test-re-test reliability from the literature for each of the standardized measures (Barroso et al. 2016; Reis, Hino & Rodriguez-Anez, 2010). Where these correlations could not be obtained, a correlation of 0.7 was assumed and sensitivity analyses were conducted to ensure that the results of the meta-analysis did not change based on these varied correlations (Morris, 2008). Results remained virtually identical when analyses were repeated using alternative correlations of 0.6 and 0.8.

A meta-analysis was then conducted to compute an overall average effect size for MBIs across the identified studies. Two largely accepted statistical models for meta-analysis exist: the fixed-effect and the random-effects models (Schmidt & Hunter, 2014). Fixed-effect models assume that there is one true effect size which is shared across all the studies within the analysis, and that any variation in observed effect sizes reflect sampling error (Borenstein, Hedges, Higgins, & Rothstein, 2010). Alternatively, random-effects models assume that a distribution of true effect sizes exist, and work to estimate the mean effect of this distribution (Borenstein et al., 2010). Here, the variation in observed effects is also considered to be due to sampling error (as in fixed-effect models), but also due to true differences in treatment effects (Riley, Higgins, & Deeks, 2010). Given the methodological variation between the selected studies (e.g. differences within interventions, across participants) a random-effects model was most appropriate and employed in the current study.

Results

The literature search identified 2,346 articles, which were screened by the first author. At this stage, 2,198 papers were excluded due to not being considered relevant to the current review, leaving 148 papers to be reviewed in detail. After the removal of duplicates ($N = 98$), 50 papers were read in full and assessed against the eligibility criteria (defined above). In total, 18 papers were considered eligible for inclusion, however data could not be obtained for four of the identified studies, and so 14 papers were included in the final meta-analyses (see figure 1).

Characteristics of included studies

Experimental design. All included studies were published between 2010 and 2017. Eight were randomised controlled trials (RCT; Bethay et al., 2013; Ferraioli & Harris, 2013; Lo et al., 2017; Lunsky et al. 2017; McConachie et al., 2014; Neece, 2014; Rayan & Ahmad, 2017; Singh et al., 2016a); five were uncontrolled trials (single group, pre-test - post-test; Hwang et al., 2015; Jones et al., 2017; Lunsky et al. 2015; Noone & Hastings, 2010; Singh et al., 2016b) and one employed a non-randomised controlled design (Ingham et al., 2013).

Quality. The methodological rigour of the studies varied. Evaluated using the EMDEBP as described above (Reichow et al. 2008), five studies were considered 'weak' quality (Hwang et al., 2015; Jones et al., 2017; Lunsky et al., 2015; Noone & Hastings, 2010; Singh et al., 2016b), six 'adequate' quality (Bethay et al., 2013; Ferraioli & Harris, 2013; Ingham et al., 2013; Lunsky et al., 2017; Neece, 2014; Singh et al., 2016a) and three 'strong' quality (Lo et al., 2017; McConachie et al., 2014; Rayan & Ahmad, 2017).

Identification

Records identified through electronic database searches
(n = 2,336)

Additional records identified through ancestral searches and review papers
(n = 10)

Screening

Records screened
(n = 2,346)

Records excluded based on abstract/title as topic or participant demographics not relevant to meta-analysis or review papers
(n = 2,198)

Eligibility

Full-text articles assessed for eligibility
(n = 148)

Full-text articles excluded:

Duplicates (n = 98)

Participant demographics not relevant (n = 2)

No stress outcome measure (10)

Non mindfulness-based intervention (2)

Qualitative (4)

Multiple Baseline (4)

Systematic review (3)

Not an experimental design (5)

Theoretical paper (1)

Descriptive data not reported (4)

Data included in a more recent trial (1)

Included

Studies included in quantitative synthesis (meta-analyses)
(n = 14)

Figure 1. Flow diagram of study selection process (PRISMA, 2009)

Professional caregivers. In total, 332 professional caregivers were included across six studies; all of whom were paid direct care staff, working within either an inpatient service (Bethay et al., 2013; Ingham et al., 2013; McConachie et al., 2014) or a community residential setting (Noone & Hastings, 2010; Singh et al., 2016a, 2016b) supporting individuals with IDD. Professional caregivers were aged 18 and over, and comprised of both qualified (e.g. nurses, social workers, psychologists) and unqualified staff (e.g. support workers). Sample sizes ranged from 33 to 120 (M= 59, SD = 34.36).

Parental caregivers. Across eight studies, 444 parental caregivers were included, all of whom were parents of individuals with IDD. Of this, 78 were fathers and the remainder were mothers. All parental caregivers were living with their child, except for 5% in one study who were living separately (Lunsky et al., 2015). All parental caregivers were aged 18 and over. Samples sizes ranged from 6 to 180 (M = 55.5, SD = 59.01).

Care recipients. Individuals whom the participants supported all had IDD; some specific diagnoses included: Autism Spectrum Disorders (ASD), developmental delay, Down's syndrome, cerebral palsy and genetic syndromes (Ferraioli & Harris, 2013; Hwang et al. 2015; Jones et al., 2017; Lo et al., 2017; Lunsky et al., 2015, 2017; Neece, 2014; Rayan & Ahmad, 2017). Other studies merely reported that the supported individuals had an IDD (Bethay et al., 2013; Ingham et al., 2013; McConachie et al., 2014; Noone & Hastings, 2010), whilst two also reported the severity of impairment (e.g. mild; Singh et al., 2016b; severe-profound; Singh et al., 2016a). Care recipients included children, adolescents and adults.

Interventions. All studies included a MBI. The interventions were all based on the core principles of mindfulness and developed from either MBSR (Kabat-Zinn, 1990) or MBCT (Hoffman et al., 2010; Teasdale et al., 1995), except for three (Bethay et al., 2013; Ingham et al., 2013; McConachie et al., 2014; Noone & Hastings, 2010) which were developed based on the core principles of ACT (Hayes, Strosahl & Wilson, 1999). All interventions included were

Table 1. *Characteristics of included studies for professional caregivers*

Author/ Year	Design	Participants	N (pre)	N (post)	Setting	Control group	Summary of intervention	Outcome measure	Findings	Follow up	Quality rating (Reichow et al., 2008)
Bethay et al. (2013).	Randomised controlled trial.	*N* = 34 Direct care staff. Professional qualification (74%)	34 I = 18 C = 16	34 I = 18 C = 16	Inpatient service.	Yes. ABA training; 9 hours delivered in a didactic fashion.	ACT + ABA training. 6 hours ACT, 3 hours ABA. Three, 3-hour group sessions. Based on core principles of ACT. Focus of sessions included: willingness and acceptance, defusion, values and committed action, present moment focus and ACT and principles of ABA.	Maslach Burnout Inventory (MBI).	Small reduction of scores in emotional exhaustion among intervention group, but not in control group. Not statistically significant.	Results remained the same at 3 month follow up. Slight reduction in control group, not statistically significant.	Adequate
Ingham et al. (2013)	Non-randomised controlled trial.	*N* = 58 Direct care staff. Nursing assistant (65%); qualified nurse (32%); student nurse (3%).	58 I = 37 C = 21	58 I = 37 C = 21	Inpatient service.	Yes. Direct care staff. Generic training.	Brief, stand-alone, intensive and interactive workshop, designed to improve psychological resilience. Experiential exercises (values based, reflective). Exploring the relationship between	Maslach Burnout Inventory (MBI).	Small improvement in burnout scores following intervention, however not statistically significant. No change in burnout scores within	None.	Adequate

		Qualification relating to ID (86%).					cognitive appraisal and emotions. Developed using elements of ACT and CBT.			comparison group.	
McCon a-chie et al., (2014)	Randomised controlled trial.	N = 120 Direct care staff. Professional qualification in ID (45%).	120 I = 66 C = 54	98 I = 53 C = 45	Inpatient service.	Yes. Direct care staff. Wait-list control.	Acceptance and mindfulness workshop. Based on core principles of ACT. Core components included: increasing mindfulness and acceptance, reducing control, defining values and creating goals. One full day workshop and one half day workshop 6 weeks later.	Staff Stressor Questionn aire (SSQ).	No change in SSQ scores.	6 weeks. Slight increase in SSQ scores.	Strong
Noone & Hasting s (2010)	Non-controlled trial. Pretest-posttest	N = 34 Direct care staff. Professional Qualification (nursing or social work: 18%)	34	34	Communi ty residential settings.	None.	Promotion of Acceptance in Carers and Teachers (PACT) workshop. 1.5 days, split over 2 dates several weeks apart. Based on the core principles of ACT. Core components included: increasing mindfulness and acceptance, reducing	Staff Stressor Questionn aire (SSQ).	Reduction in stress scores, however not statistically significant.	None.	Weak

		Basic level qualifications (82%)					control, defining values and creating goals.				
Singh et al. (2016a)	Randomised controlled trial.	$N = 75$ Direct care staff.	75 I = 37 C = 38	75 I = 37 C=38	Community residential settings.	Yes. Training as usual (TAU): ABA training	Mindfulness-Based Positive Behavior Support (MBPBS). Three parts over 10 weeks; one 8 hour day; five 8 hour days; one 8 hour day. Mindfulness training on the four immeasurables. Training focused on using PBS within the context of mindfulness practices.	Perceived Stress Scale -10 (PSS-10)	Significant reduction in stress in intervention group (but not control) with a large effect size (2.6).	None	Adequate
Singh et al. (2016b)	Uncontrolled trial. Pretest-posttest	$N = 33$ Direct care staff.	33	33	Community residential settings.	None.	Mindfulness-Based Positive Behaviour Support. Three parts over 10 weeks; one 8 hour day; five 8 hour days; one 8 hour day. Mindfulness training on the four immeasurables. Training focused on using PBS within the context of mindfulness practices.	Perceived Stress Scale -10 (PSS-10)	Statistically significant reduction in stress scores from pre- to post-intervention.	Further significant reductions at 30 week follow up.	Weak

Table 2. *Characteristics of included studies for parental caregivers*

Author/ Year	Design	Participants	N (pre)	N (post)	Setting	Control group	Summary of intervention	Outcome measure	Findings	Follow up	Quality rating (Reichow et al., 2008)
Ferraioli & Harris (2013)	Randomised controlled trial	*N* = 15 Parents of children (under 18) with ASD (living at home).	15 I = 6 C = 9	15 I = 6 C = 9	Community	Yes. Skills-based parent training.	Mindfulness-Based Parent Training. 8 weekly, 2-hour sessions with weekly home practice. Based on MBCT and mindfulness module from Linehan's (1993) training manual.	Parenting Stress Index – Short Form (PSI-SF).	Significant reductions in stress scores among intervention group but not controls.	Reduced stress scores maintained at 3 month follow up, although not statistically significant.	Adequate
Hwang et al. (2015)	Uncontrolled trial.	*N* = 6 Mother-child dyads. Children with a diagnosis of ASD (living at home).	6	6	Community.	None.	Mindfulness Training for Mothers (for mothers only, not children). 8 week program, with weekly 2.5 hour sessions. Weekly home practice. Intervention based on MBSR.	Parenting Stress Scale (PSS).	Significant reduction in parental stress post-intervention.	15 months later, following a period of parent-mediated mindfulness for children, there was a further reduction in parental stress scores.	Weak

19

Study	Design	Sample			Setting	Control	Intervention	Measure	Outcome	Follow-up	Quality
Jones et al. (2017)	Uncontrolled trial.	$N = 21$ Parents of children (4-16) with ASD or ID (all living at home).	21	21	Community.	None.	Mindfulness-Based Well-Being course for parents (MBW-P). Based on MBCT and MBSR. 8 week program, with weekly 2-hour sessions. Weekly home practice.	DASS-21 stress subscale.	Significant reduction in stress scores post-intervention.	None.	Weak
Lo et al. (2017)	Randomised controlled trial.	$N = 180$ Parents of children with DD (all living at home).	180 $I = 91$ $C = 89$	180 $I = 91$ $C = 89$	Community.	Yes. No intervention.	Brief mindfulness training. 6 weekly sessions, each lasting 1.5 hours. Based on two mindfulness parenting programmes (MY Mind and Mindfulness-Enhanced Strengthening Families Program; Bogels, 2013; Coatsworth et al., 2014) developed from MBCT and MBSR.	Parenting Stress Index - Short Form (PSI-SF).	Significant reduction in stress scores among the intervention group.	None.	Strong
Lunsky et al. (2015)	Uncontrolled trial.	$N = 22$ Parents of adolescents or adults with IDD	22	22	Community	None.	Mindfulness group. Adapted from MBCT. Six, 2-hour sessions held weekly. Weekly home practices.	DASS-21 Stress subscale.	Significant reduction in reported stress on the DASS-21 post-intervention.	None.	Weak

		(95% living at home).									
Lunsky et al. (2017)	Randomised controlled trial.	*N* = 50 Parents of adults (16-40) with ASD/DD (living at home)	46 I = 26 C = 20	46 I = 26 C = 20	Community	Yes. Support and information group.	Mindfulness-based intervention. Adapted from MBCT. Initial orientation session followed by six, weekly 2-hour sessions.	DASS-21 stress subscale.	Significant reduction of stress scores within intervention group but not control.	Improvements maintained at 3 month follow up.	Adequate
Neece (2014)	Randomised controlled trial	*N* = 46 Parents of children aged 2.5-5 years with DD (living at home).	46 I = 21 C = 25	46 I = 21 C = 25	Community	Yes. Wait list control.	MBSR. 8 weekly, 2-hour sessions, a day long 6-hour meditation after class 6 and weekly home practice.	Parenting Stress Index – Short Form. (PSI-SF).	Intervention group demonstrated significantly lower stress scores at post intervention.	None.	Adequate
Rayan & Ahmad (2017)	Randomised controlled trial.	*N* = 104 Parents of children with ASD (living at home).	104 I = 52 C = 52	104 I = 52 C = 52	Community	Yes. No intervention.	Mindfulness-Based intervention. Adapted from Ferraioli & Harris (2013). 5 week program. 2 Two in person sessions, each 150 mins. Followed by three telephone follow up conversations for 30 mins each. Weekly home practice.	Depression, Anxiety and Stress Scale (DASS-21).	Significant reduction of stress scores in the intervention group, but not control group, post-intervention.	None.	Strong

face-to-face interventions, with the exception of one, which included two face-to-face sessions followed by three telephone consultations (Rayan & Ahmad, 2017). The length of intervention varied significantly from a brief stand-alone session (Ingham et al., 2013) to being spread over 10 weeks (Singh et al., 2016a, 2016b). The majority of interventions included weekly sessions (between 1.5-2.5 hours) spread over six to eight weeks (Ferraioli & Harris, 2013; Hwang et al., 2015; Jones et al., 2017; Lo et al., 2017; Lunsky et al., 2015, 2017; Neece, 2014). Two interventions included a similar number of sessions; however, they were spread across 10 weeks, with two one-day sessions, intercepted by a five-day intense training period (Singh et al., 2016a, 2016b). Three interventions included a stand-alone session (Ingham et al., 2013), two of which also included a booster session some weeks later (McConachie et al., 2014; Noone & Hastings, 2010). Bethay et al. (2013) implemented an intervention across three, three-hour sessions. All interventions, except the stand-alone workshops, required participants to engage with home practices between sessions.

Control conditions. Nine studies included a control condition. These ranged from no intervention received (Lo et al., 2017; Rayan & Ahmad, 2017) to wait-list controls (McConachie et al. 2014; Neece, 2014) and training as usual (Bethay et al., 2013; Ferraioli & Harris 2013; Ingham et al., 2013; Lunsky et al., 2017; Singh et al., 2016a). Training as usual included interventions such as: Applied Behaviour Analysis; definitions and contexts of IDD, support and information groups and skills based parent training.

Outcome measures. All studies used a measure of stress or burnout, these included: The Parenting Stress Index Short Form (PSI-SF; Abidin, 1995) The Depression Anxiety Stress Scale-21 (DASS-21; Lovibond & Lovibond, 1995); The Parental Stress Scale (PSS; Berry & Jones, 1995); The Staff Stressor Questionnaire (SSQ; Hatton et al., 1999); The Perceived Stress Scale (PSS; Cohen et al., 1983) and the Maslach Burnout Inventory (MBI; Maslach et al., 1996). Data was collected at a variety of timepoints across studies, however all studies provided

data at baseline and immediately post-intervention, which was the data utilised within this review. A summary of study characteristics is provided in Tables 1 and 2.

Meta-analyses

Effects of MBIs for parental caregivers

Effect sizes for the eight included studies ranged from -0.13 to -2.46. The random-effects model yielded a pooled effect size (SMC) of -0.46 (95% CI: -0.68 to -0.07, $p < .01$); representing a statistically significant small to moderate effect of MBIs in reducing stress among parental caregivers. Heterogeneity tests were significant (Q = 18.66, $p < .01$, I^2 = 53.7%), confirming the presence of heterogeneity (variability in effect sizes) amongst the included studies. See Figure 2 for a forest plot summarising this meta-analysis.
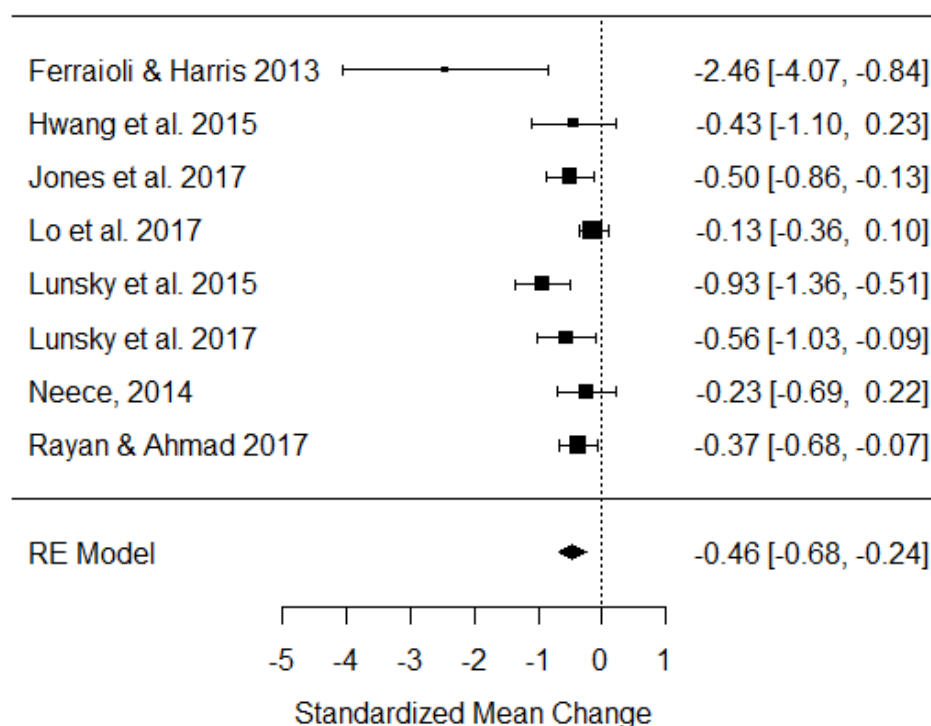
Figure 2. Meta-analysis of studies using MBIs to reduce stress among parental caregivers of individuals with IDD.

Publication bias is a common type of bias, which occurs when the direction and statistical significance of findings influence the likelihood of studies being published (i.e.

smaller studies revealing non-significant results are less likely to be published; Rothstein, Sutton, & Borenstein, 2005). To assess for the presence of publication bias, a funnel plot presenting the standard error against effect size for each of the included studies was visually reviewed (see Figure 3). This showed some possible asymmetry, highlighting one isolated study, which included a small sample, and demonstrated a large effect size with a large standard error (Ferraioli & Harris, 2013). This heterogeneity may reflect chance variability within studies, or it may be indicative of a slight publication bias in the literature (Stern et al., 2011).
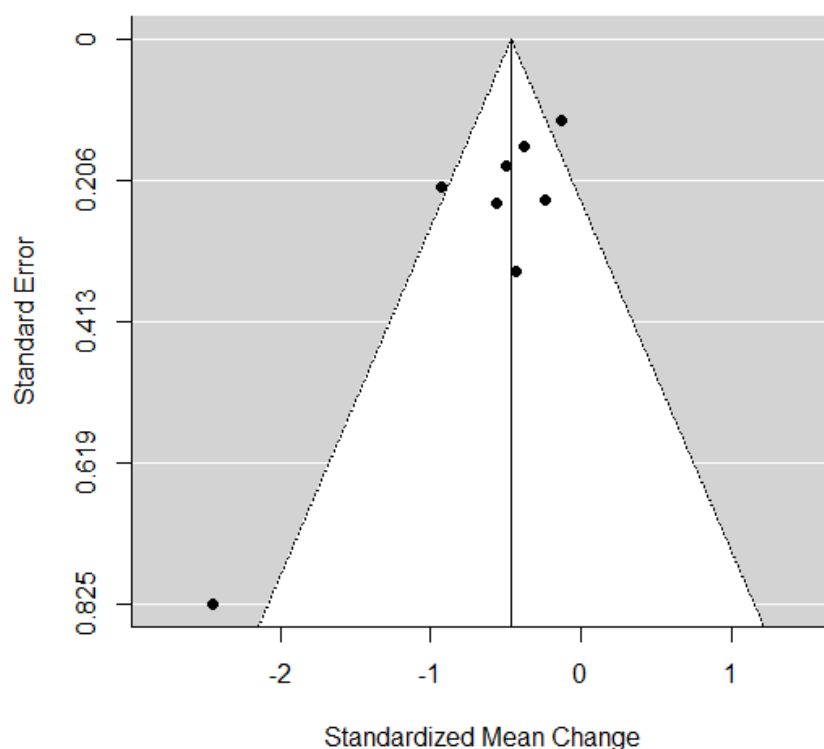
Figure 3. Funnel plot of all studies included in the meta-analysis for the efficacy of MBI in reducing stress among parental caregivers.

To explore whether the results of the analysis were unduly skewed by this study, the analysis was re-run with the study excluded. Similar to the initial results, the analysis yielded a pooled SMC of -0.42 (95% CI: -0.63 to -0.21, p, < .01), representing a small to moderate effect of MBIs in reducing stress among parental caregivers. With the study excluded, tests of heterogeneity were non-significant (Q = 12.31, p = 0.06, I^2 = 51.42%), suggesting that this study contributed to the observed heterogeneity. Heterogeneity tests were however, only just

non-significant, indicating that heterogeneity was likely still present among the other included studies.

Effects of MBIs for professional caregivers

Effect sizes of interventions on stress ranged from -0.02 to -2.76. The random-effects model yielded a pooled effect size (SMC) of -0.78 (95% CI: -0.78 to 0.14, $p = 0.10$); representing a non-significant effect of MBIs in reducing stress among professional caregivers. See Figure 4 for a forest plot summarising the meta-analysis. As is highlighted by the forest plot two studies (Sing et al., 2016a; 2016b) yielded significantly larger effects than the others which found minimal effects. This is further explored in the discussion section below.
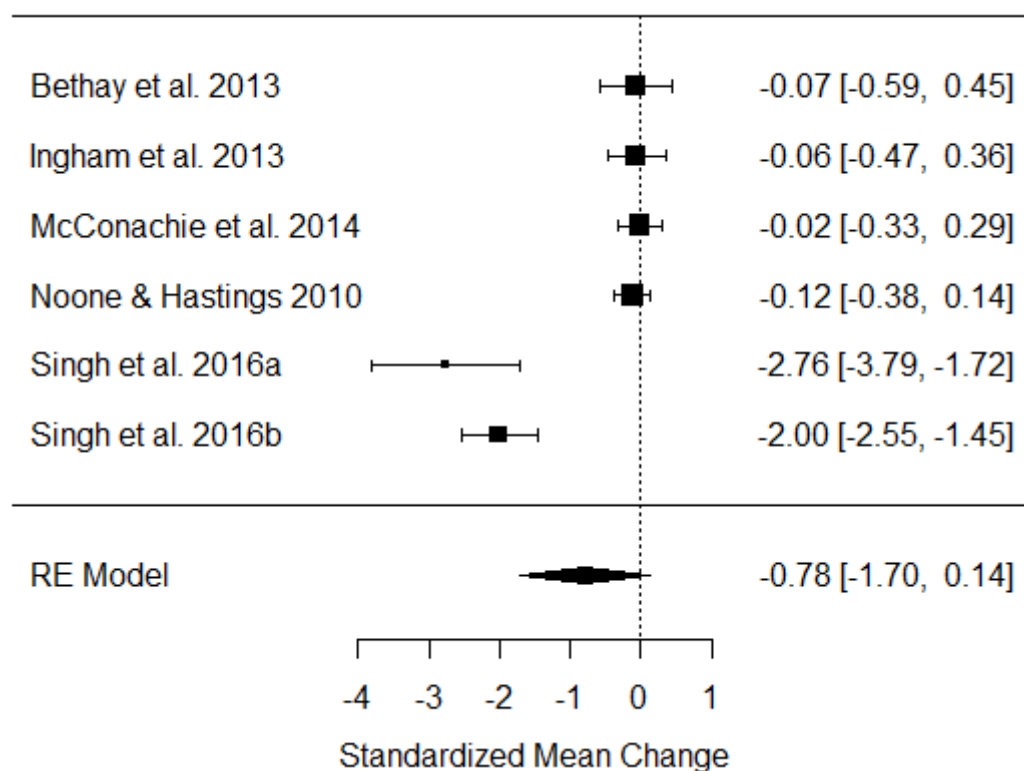
Figure 4. Meta-analysis of studies using MBIs to reduce stress among professional caregivers of individuals with IDD.

Discussion

To our knowledge, this is the first systematic review to include meta-analyses on the efficacy of MBIs for caregivers of individuals with IDD. The current review extends the findings of existing narrative reviews by combining the effect sizes of existing studies to estimate an overall effect for parental and professional caregivers.

Parental caregivers

With regard to parental caregivers, the meta-analysis revealed that MBIs are effective in reducing stress, with a small to moderate effect. These findings support previous reviews which have also shown MBIs to be effective in managing stress among parents of individuals with IDD (e.g. Hwang & Kearney, 2014; Ryan & Ahmad, 2017). However, only eight studies met inclusion criteria, of which only two were considered strong quality, with the remainder adequate and weak; thus, indicating a high risk of bias among the literature which poses challenge to the validity of the data. Whilst the paucity of research within this field meant it was not possible to conduct a meta-analysis solely including randomised controlled trials, this raises important issues to be considered when interpreting the results. For example, uncontrolled studies are more susceptible to the influence of confounding variables, and therefore findings need to be interpreted with caution. Whilst results indicate significant reductions in stress outcomes consistently across studies, the methodological weaknesses of the included studies (namely the absence of control groups) makes it difficult to draw comprehensive conclusions. The current review therefore supports that MBIs may be effective in reducing stress among parental caregivers, at least in the short term, however further research is warranted to further explore this and strengthen our understanding.

Professional caregivers

With regard to professional caregivers, the meta-analysis revealed no significant effect of MBIs in reducing perceived stress. Results indicated that four of the six studies found a minimal effect of MBIs on reducing stress (Bethay et al., 2013; Ingham et al., 2013; McConachie et al., 2014; Noone & Hastings, 2010), whereas two studies (Singh et al., 2016a; 2016b) found a large effect. These results are somewhat unsurprising, given the inconsistencies in stress outcomes highlighted among the existing literature pertaining to MBIs among professional caregivers (e.g. Hwang & Kearney, 2014; Ó Donnchadha, 2018). Findings are thus consistent with previous reviews, and support that there are discrepancies among stress outcomes for professional caregivers, making it difficult to estimate a valid overall effect size.

Interestingly, the two studies which yielded notably larger effects, implemented the same MBPBS intervention. MBPBS implemented in Singh et al. (2016a) and (2016b) is a notably longer and more intense intervention than those implemented in the other studies. MBPBS included three separate parts over 10 weeks; one eight-hour workshop, with a practice phase followed by five consecutive eight-hour workshops, followed by another practice phase and a final eight-hour workshop. All other studies included interventions which were significantly shorter and less intense, ranging from a one-day workshop, to one and a half days and three, three-hour lectures. This suggests the possible presence of a dose-response relationship, in that the effect of MBIs in reducing stress may be moderated by the length and/or intensity of the intervention. This might be understandable given that emphasis is placed on long-term practice of mindfulness skills in order for effects to be noticed (Singh et al., 2009). This may also help to explain why a significant overall effect was yielded among parental caregivers but not professional caregivers, as all interventions for parental caregivers were considerably longer/more intense. Whilst this may be true, it should be noted that both of these studies were considered to have methodological weaknesses; with Singh et al. (2016a) rated

only as adequate quality, and Singh et al. (2016b) rated as weak, posing challenge to the validity of the findings. For example, Singh et al. (2016b) employed an uncontrolled design and thus we are unable to infer that the observed changes in perceived stress were due to the intervention as opposed to other factors.

Alternatively, it may be that MBIs are not effective in reducing stress among professional caregivers, which may be understandable given the focus on acceptance rather than change in MBIs. It is possible that caregivers begin to accept, rather than attempt to change or remove, inherent work-stress factors, and as such, their perception of stress remains unchanged, but their relationship with such experiences may be improved. Indeed, findings which highlight stable or increased perceptions of stress and reduced psychological distress support this hypothesis (e.g. McConachie et al., 2014; Noone & Hastings, 2010).

Additionally, the studies which yielded either no effect, or small effects which were non-significant all implemented ACT-informed interventions, whereas MBPBS (which yielded large effects) involves a synergy of mindfulness and positive behaviour support. Thus, inherent differences in the theoretical underpinnings of the interventions may also be a possible factor contributing to the observed discrepancies.

Further research is thus warranted to understand the effects of MBIs on reducing stress among professional caregivers, and investigate the discrepancies within the existing literature. It is important that future research employs methodologically strong quality trials to enable more comprehensive conclusions to be drawn.

Limitations

It is important that the findings of the current review are considered in light of a number of methodological points. Firstly, the meta-analyses included a small sample of studies, each with relatively small sample sizes which limit the generalisability of the findings. In particular, there

was a distinct lack of fathers among the parental caregiver samples, and thus it may not be appropriate to assume the findings are representative of this population. Conversely, the heterogeneity present amongst professional caregivers (e.g. support staff, nurses, social workers, psychologists) poses different challenges to the generalisability of the findings given that perceived stress amongst professional caregivers may differ according to profession (Noone et al., 2010).

Although these preliminary findings support that MBIs are effective in reducing stress among parental caregivers, the current study did not include measures of state mindfulness, therefore it is unclear whether changes in stress scores were the result of increased levels of mindfulness, or another aspect of the intervention.

Given the paucity of research within this field, the meta-analyses included a variety of different study designs (RCTs, non-randomised controlled trials, uncontrolled trials). This likely contributed to the heterogeneity observed within some of the analyses, and makes it difficult to accurately compare study outcomes. A more stringent approach to inclusion would have been preferred, however the dearth of research within the field meant this was not possible. Multiple-baseline designs were not included in this review, meaning that a wealth of available data was not captured, which could offer important contributions to the evidence base. The methodological rigour of the included studies also varied, and whilst some were considered to be strong (3) or adequate quality (6), a number were assessed as being weak quality (5).

A further limitation is the lack of follow up data. Less than half of the included studies provided follow-up data, and for those which did, the time period varied from six weeks to 15 months. The current findings are thus limited to the short-term effects of MBIs on stress among caregivers of individuals with IDD. It is not possible to infer that such findings are maintained in the longer term. This is disappointing given that the effects of mindfulness are thought to

develop following long-term practice, and is something that should be addressed in future research.

Finally, further limitations relate to limited outcome measures. The current review focused only on stress outcomes; and whilst this is important given the elevated levels of stress among this population, other outcomes measures are equally as important to consider. Measures of psychological distress would be valuable given the possibility that increased acceptance may mean that perceived stress remains consistent, but associated distress is reduced. Additionally, given the possibility of a transactional relationship between caregiver and recipient, outcomes for care recipients are equally important and need to be considered. Whilst some of the included studies reported on such outcomes, including behaviour that challenges and use of physical restraint, there was insufficient data to include this in the current analysis.

Future research

Research within this field remains in its infancy and the review highlights that more research is warranted. In particular, more RCTs are required, that include larger, more diverse samples, and investigate the longer-term effects of MBIs. Future research needs to evaluate a range of appropriate outcome measures, for both caregivers and care recipients. To date, the efficacy of specific MBIs is unknown, as is the efficacy of MBIs generally in comparison to existing interventions such as CBT or behavioural support programmes and should be explored in future research. Furthermore, it would be beneficial to further explore specific intervention components which promote therapeutic change. The current findings suggest that the length and intensity of intervention may be positively correlated with positive outcomes, however this is based upon a small number of findings. As the research develops, studies should explore potential moderating and mediating factors (e.g. length/intensity of intervention, caregiver profession/gender, group versus 1:1, participant responsiveness), for both professional and

parental caregivers individually. This will allow the evidence base to be further develop and allow us to understand if the different groups require specific adaptations to the interventions.

Conclusions

The literature within this field remains very much in its infancy, however preliminary findings indicate that MBIs may be effective in reducing stress among parental caregivers, at least in the short term. For professional caregivers, findings are more mixed. Unfortunately, the paucity of research in this field meant that a heterogeneous sample of studies, with varying levels of methodological quality, were included in the analysis, which makes it difficult to draw comprehensive conclusions. Further research is thus warranted in order to further develop the evidence base; future research should endeavour to include highly controlled trials to further understand the effects of MBIs on reducing stress in caregivers of individuals with IDD.

Declaration of Conflicting Interests

The authors declare that they have no conflict of interest.

References

[* signifies studies included in the meta-analyses]

Abidin, R. R. (1995). *Parenting stress index* (3rd ed.). Odessa: Psychological Assessment
    Resources.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-
    school children with and without developmental delay: behaviour problems and
    parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217-
    230. 10.1046/j.1365-2788.2003.00484.x

Barroso, N. E., Hungerford, G. M., Garccia, D., Graziano, P. A., & Bagner, D. M. (2016).
    Psychometric Properties of the Parenting Stress Index-Short Form (PSI-SF) in a High-
    Risk Sample of Mothers and their Infants. *Psychological Assessment, 28*(10), 1331-
    1335. doi: 10.1037/pas0000257

Becker, B. J. (1988). Sythesizing standardized mean-change measures. *British Journal of
    Mathematical and Statistical Psychology, 41,* 257-278. doi: 10.1111/j.2044-
    8317.1988.tb00901.x

Berry, J. D., & Jones, W. H. (1995). The parental stress scale: Initial psychometric evidence.
    Journal of Social and Personal Relationships, 12, 463-472.

*Bethay, J. S., Wilson, K. G., Schnetzer, L. W., Nassar, S. L., & Bordieri, M. J. (2013). A
    Controlled Pilot Evaluation of Acceptance and Commitment Training for Intellectual
    Disability Staff. *Mindfulness, 4*(2), 113-121. doi: 10.1007/s12671-012-0103-8

Birnie, K., Garland, S. N., & Carlson, L. E. (2010). Psychological benefits for cancer patients
    and their partners participating in mindfulness-based stress reduction (MBSR).
    Psycho-Oncology, 19(9), 1004-1009. doi: 10.1002/pon.1651

Bögels, S. M. (2013). *MYmind mindfulness for children and adolescents with ADHD: therapist's manual.* Amsterdam: university of Amsterdam.

Borenstein, M., Hedges, L. V., Higgins, J. P. T., & Rothstein, H. R. (2010). A basic introduction to fixed-effect and random-effects models for meta-analysis. *Research Synthesis Methods, 1*(2), 97-111. doi: 10.1002/jrsm.12

Cachia, R. L., Anderson, A., & Moore, D. W. (2016). Mindfulness, Stress and Well-Being in Parents of Children with Autism Spectrum Disorder: A Systematic Review. *Journal of Child and Family Studies, 25*(1), 1-14. doi: 10.1007/s10826-015-0193-8

Chapman, M. J., Hare, D. J., Caton, S., Donalds, D., McInnis, E., & Mitchell, D. (2013). The use of Mindfulness with People with Intellectual Disabilities: a Systematic Review and Narrative Analysis. *Mindfulness, 4*(2), 179-189. doi: 10.1007/s12671-013-0197-7

Cash, T. V., Ekouevi, V. S., Kilbourn, C., & Lageman, S. K. (2015). Pilot Study of a Mindfulness-Based Group Intervention for Individuals with Parkinson's Disease and Their Caregivers. *Mindfulness, 7*(2), 361-371. doi: 10.1007/s12671-015-0452-1

Chien, E. T., & Thompson, D. R. (2014). Effects of a mindfulness-based psychoeducation programme for Chinese patients with schizophrenia: 2-year-follow-up. *The British Journal of Psychiatry, 205*(1), 52-59. doi: 10.1192/bjp.bp.113.134635

Chiesa, A., & Settetti, A. (2009). Mindfulness-Based Stress Reduction for Stress Management in Healthy People: A Review and Meta-Analysis. *The Journal of Alternative and Complementary Medicine, 15*(5). 593-600.

Coatsworth, J. D., Duncan, L. G., Berrena, E., Bamberger, K. T., Loeschinger, D., Greenberg, M. T., & Nix, R. L. (2014). The mindfulness-enhanced strengthening families program: integrating brief mindfulness activities and parent training within an

evidence-based prevention program. *New Directions for Youth Development,*
2014(142), 45-58.

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences* (2nd ed.). Hillsdale,
NJ: Erlbaum.

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress.
Journal of Health and Social Behaviour, 24(4), 385-396. doi:

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*(1), 155-159. doi:
10.1037/0033-2909.112.1.155

Cohen, S., Kamarck, T., & Memelstein, R. (1983). A global measure of perceived stress.
Journal of Health and Social Behavior, 24(4), 385-396. doi: 10.2307/2136404

Crawford, M. J., Adedeji, T., Price, K., & Rutter, D. (2010). Job satisfaction and burnout
among staff working in community-based personality disorder services. *International*
Journal of Social Psychiatry, 56(2), 196-206. doi: 10.1177/0020764009105702

Devereux, J., Hastings, R., Noone, S. J., Firth, A., & Totsika, V. (2009). Social support and
coping as mediators or moderators of the impact of work stressors on burnout in
intellectual disability support staff. *Research in Developmental Disabilities, 30*(2),
367-377. doi: 10.1016/j.ridd.2008.07.002

Ellingsen, R. R., Baker, B. L., Blacher, J., & Crnic, K. (2014). Resilient parenting of
preschool children at developmental risk. *Journal of Intellectual Disability Research,*
58(7), 664-678. doi: 10.1111/jir.12063

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X-H., & Abbott, R. (2009). Parenting
stress and psychological functioning among mothers of preschool children with

autism and developmental delay. *Autism, 13*(4), 375-387. doi: 10.1177/1362361309105658

Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., & Munson, J. (2013). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorder. *Brain & development, 35*(2), 133-138. doi: 10.1016/j.braindev.2012.10.004

*Ferraioli, S. J., & Harris, S. L. (2013). Comparative Effects of Mindfulness and Skills-Based Parent Training Programs for Parents of Children with Autism: Feasibility and Preliminary Outcome Data. *Mindfulness, 4*(2), 89-101. doi: 10.1007/s12671-012-0099-0

Flaxman, P. E., Bond, F. W., & Livheim, F. (2013). *The mindful and effective employee: An acceptance and commitment therapy training manual for improving well-being and performance.* Oakland, CA: New Harbinger Publications.

Francis, R. (2013). *Report of the Mi-Staffordshire NHS Foundation Trust Public Inquiry.* London: The Stationery Office.

Gardner, B., Rose, J., Mason, O., Tyler, P., & Cushway, D. (2005). Cognitive therapy and behavioural coping in the management of work-related stress: An intervention study? *Work and Stress, 19*(2), 137-152. doi: 10.1080/02678370500157346

Gray-Stanley, J. A. (2009). *Stress and coping of direct care workers serving adults with intellectual/developmental disabilities.* Chicago: University of Illinois.

Hastings, R. P., & Beck, A. (2004). Practitioner Review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry, 45*(8), 1338-1349. doi: 10.111/j.1469-7610.2004.00357.x

Hastings, R. P., & Manikam, R. (2013). Mindfulness and acceptance in developmental

   disabilities: Introduction to the special issue. *Mindfulness, 4*(2), 85-88. doi:

   10.1007/s12671-013-0207-9

Hatton, C., Rivers, M., Mason, H., Mason, L., Kiernan, C., Emerson, E., Alborz, A. &

   Reeves, D. (1999). Staff stressors and staff outcomes in services for adults with

   intellectual disabilities: the staff stressor questionnaire. *Research in Developmental

   Disabilities, 20*(4), 269-285.

Hayes, S. C. (1987). A Contextual Approach to Therapeutic Change. In N. Jacobson (Ed.),

   Psychotherapists in Clinical Practice: Cognitive and Behavioural perspectives (pp.

   327-387). New York: Guilford.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy:

   An Experiential Approach to Behaviour Change.* New York: Guilford Press.

Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An

   experiential approach to behavior change.* New York, NY: Guildford Press.

Higgins, J. P. T., & Deeks, J. J. (Eds.). (2011). Chapter 7: Selecting studies and collecting

   data. In: J.P.T. Higgins & S. Green (Eds.), *Cochrane Handbook for Systematic

   Reviews of Interventions*. Retrieved from: http://handbook-5-1.cochrane.org/

Hoffman, S. G., Sawyer, A. T., Witt, A. A., & Oh, D. (2010). The Effect of Mindfulness-

   based Therapy on Anxiety and Depression: A Meta-Analytic Review. *Journal of

   Consulting and Clinical Psychology, 78*(2), 169-183. doi: 10.1037/a0018555

Hwang, Y-S., & Kearney, P. (2014). Mindful and Mutual Care for Individuals with

   Developmental Disabilities: A Systematic Literature Review. *Journal of Child and

   Family Studies, 23*(3), 497-509. doi: 10.1007/s10826-012-9707-9

*Hwang, Y-S., Kearney, P., Klieve, H., Lang, W., & Roberts, J. (2015). Cultivating Mind: Mindfulness Interventions for Children with Autism Spectrum Disorder and Problem Behaviours and Their Mothers. *Journal of Child and Family Studies, 24*(10), 3093-3106. doi: 10.1007/s10826-015-0114-x

*Ingham, B., Riley, J., Nevin, H., Evans, G., & Gair, E. (2013). An initial evaluation of direct care staff resilience workshops in intellectual disabilities services. *Journal of Intellectual Disabilities, 17*(3), 214-222. doi: 10.1177/1744629513494642

Jahoda, A., Wilner, P., Pert, C., & MacMahon, K. (2013). From causes of aggression to intervention: the importance of context. In R. Hastings & J. Rojahn (Eds.). *International review of Research in Intellectual Disabilities* (pp. 69-104). Amsterdam: Elsevier.

*Jones, L., Gold, E., Totsika, V., Hastings, R. P., Jones, M., Griffiths, A. & Silverton, S. (2017). A mindfulness parent well-being course: evaluation of outcomes for parents of children with autism and related disabilities recruited through special schools. *European Journal of Special Needs Education, 33*(1), 16-30. doi: 10.1080/08856257.2017.1297571

Kabat-Zinn, J. (1990). *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain and Illness.* New York: Dell.

Kabat-Zinn, J. (2003). Mindfulness-Based interventions in Context: Past, Present, and Future. *Clinical Psychology: Science and Practice, 10*(2), 144-156.

Kor, P. P. K., Chien, W. T., Liu, J. Y. W., & Lai, C. K. Y. (2018). Mindfulness-Based Intervention for Stress Reduction of Family Caregivers of People with Dementia: A Systematic Review and Meta-Analysis. *Mindfulness, 9*(1), 7-22. doi: 10.1007/s12671-017-0751-9

Korsitas, S., Iacano, T., Carling-Jenkins, R., & Chan, J. (2010). *Exposure to challenging behaviour and support worker/house supervisor well-being.* Melbourne: The Centre for Developmental Disability Health Victoria.

Kristeller, J. L., Baer, R. A., & Quillian-Wolever, R. (2015). Mindfulness-Based Approaches to Eating Disorders. In: R. A. Baer (Ed.). *Mindfulness-Based Treatment Approaches: Clinician's Guide to Evidence Base and Applications* (pp. 75-89). London, UK: Elsevier.

Kushlick, A., trower, P., & Dagmand, D. (1997). Applying cognitive behavioural approaches to the carers of people with learning disabilities. In: B. S. Kroese, D. Dagnan & K. Loumides (Eds.). *Cognitive Behaviour Therapy for People with Learning Disabilities* (pp. 145-165). London, UK: Routledge.

Lach, L. M., Kohen, D. E., Garner, R. E., Brehaut, J. C., Miller, A. R., Klassen, A. F., et al. (2009). The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disability and Rehabilitation, 31*(8), 607-618. doi: 10.1080/09638280802242163

Leoni, M., Corti, S., Cavagnola, R., Healy, O., & Noone, S. J. (2016). How acceptance and commitment therapy changed the perspective on support provision for staff working with intellectual disability. *Advances in mental health and intellectual disabilities, 10*(1), 59-73.

Lindo, E., Kliemann, K. R., Combes, B. H., & Frank, J. (2016). Managing Stress Levels of Parents of Children with Developmental Disabilities: A Meta-Analytic Review of Interventions. *Family Relations, 65*(1), 207-224. doi: 10.111/fare.12185

*Lo, H. H. M., Chan, S. K. C., Szeto, M. P., Chan, C. Y. H., Choi, C. W. (2017). A Feasibility Study of a Brief Mindfulness-Based Program for Parents of Preschool

Children with Developmental Disabilities. *Mindfulness, 8*(6), 1665-1673. doi: 10.1007/s12671-017-0741-y

Lovas, D. A., Pajer, K., Chorney, J. M., Vo, D. X., Howlett, M., Doyle, A., & Huber, A. (2017). Mindfulness for adolescent chronic pain: a pilot feasibility study. *Journal or Child & Adolescent Mental Health, 29*(2), 129-136. doi: 10.2989/17280583.2017.1355807

Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the depression anxiety stress scales.* Sydney: Psychological Foundation.

*Lunsky, Y., Robinson, S., Reid, M., Palucka, A. (2015). Development of a Mindfulness-Based Coping with Stress Group for Parents of Adolescents and Adults with Developmental Disabilities. *Mindfulness, 6*(6), 1335-1344. doi: 10.1007/s12671-015-0404-9

*Lunsky, Y., Hastings, R. P., Weiss, J. A., Palucka, A. M., Hutton, S., & White, K. (2017). Comparative Effects of Mindfulness and Support and Information group Interventions for Parents of Adults with Autism Spectrum Disorder and Other Developmental Disabilities. *Journal of Autism and Developmental Disorders, 47*(6), 1769-1779. doi: 10.1007/s10803-017-3099-z

MacDonald, E., E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological acceptance mediates the impact of the behaviour problems of children with intellectual disability on fathers' psychological adjustment. *Journal of Applied Research in Intellectual Disabilities, 23*(1), 27-37. doi: 10.1111/j.1468-3148.2009.00546.x

Maslach, C., Jackson, S. E., & Leiter, M. P. (1996). *The Maslach Burnout Inventory manual* (3rd ed.). Palo Alto, CA: Consulting Psychologists Press.

*McConachie, D. A. J., McKenzie, K., Morris, P. G., & Walley, R. M. (2014). Acceptance
and mindfulness-based stress management for support staff caring for individuals with
intellectual disabilities, *Research in Developmental Disabilities, 35*(6), 1216-1227.
doi: 10.1016/j.ridd.2014.03.005

McNair, L., Woodrow, C., & Hare, D. (2016). Dialectical Behaviour Therapy [DBT] with
people with Intellectual Disabilities: A Systematic Review and Narrative Analaysis.
Journal of Applied Research in Intellectual Disabilities, 30(5), 787-804. doi:
10.1111/jar.12277

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., The PRISMA Group. (2009). Preferred
Reporting Items for Sytematic Reviews and Meta-Analyses: The PRISMA Statement.
PLOS Medicine, 6(7): e1000097. doi: 10.1371/journal.pmed1000097

Morris, S. B. (2000). Distribution of the standardized mean change effect size for meta-
analysis on repeated measures. *British Journal of Mathematical and Statistical
Psychology, 53*(1), 17-29. doi: 10.1348/000711000159150

Morris, S. B. (2008). Estimating Effect Sizes From Pretest-Posttest-Control Group Designs.
Organizational Research Methods, 11(2), 364-386. doi: 10.1177/1094428106291059

Namkung, E. H., Song, J., Greenberg, J. S., Mailick, M. R., & Floyd, F. J. (2015). The
relative risk if divorce in parents of children with developmental disabilities: impact
of lifelong parenting. *American Journal on Intellectual and Developmental
Disabilities, 120*(6), 514-526. doi: 10.1352/1944-7558-120.6.514

*Neece, C. L. (2014). Mindfulness-Based Stress Reduction for Parents of Young Children
with Developmental Delays: Implications for Parental Mental Health and Child
Behaviour Problems. *Journal of Applied Research in Intellectual Disabilities, 27*(2),
174-186. doi: 10.1111/jar.12064

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behaviour problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities, 117*(1), 48-66. doi: 10.1352/1944-7558-117.1.48

Nickmat, A. W., Ahmad, M., & Razali, S. (2008). Stress and psychological wellbeing among parents of children with autism spectrum disorder. *ASEAN Journal of Psychiatry, 9*(2), 65-72.

*Noone, S. J., & Hastings, R. P. (2010). Using Acceptance and Mindfulness-Based Workshops with Support Staff Caring for Adults with Intellectual Disabilities. *Mindfulness, 1*(2), 67-73. doi: 10.1007/s12671-010-0007-4

Ó Donnchadha, S. (2018). Stress in caregivers of individuals with intellectual or developmental disabilities: A systematics review of mindfulness-based interventions. *Journal of Applied Research in Intellectual Disabilities, 31*(2), 18-192. doi: 10.1111/jar.12398

R Core Team. (2017). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. https://www.r-project.org/

*Rayan, A., & Ahmad, M. (2017). Effectiveness of Mindfulness-Based Intervention on Perceived Stress, Anxiety, and Depression Among Parents of Children with Autism Spectrum Disorder. *Mindfulness, 8*(3), 677-690. doi: 10.1007/s12671-016-0595-8.

Reichow, B. (2011). Development, Procedures, and Application of the Evaluative Method for Determining Evidence-Based Practices in Autism. In B. Reichow, P. Doehring, D. V. Cicchetti & F. R. Volkmar (Eds.), *Evidence-Based Practices and Treatments for Children with Autism* (pp. 25-39). New York: Springer.

Reichow, B., Volkmar, F. R., & Cicchetti, D. V. (2008). Development of the Evaluative Method for Evaluating and Determining Evidence-Based Practices in Autism. *Journal of Autism and Developmental Disorders, 38*(7), 1311-1319. doi: 10.1007/s10803-007-0517-7

Reis, R. S., Hino, A. A. F., & Rodriguez-Anez, C. R. (2010). Perceived Stress Scale: Reliability and Validity Study in Brazil. *Journal of Health Psychology, 15*(1), 107-114. doi: 10.1177/1359105309346343

Riley, R. D., Higgins, J. P. T., & Deeks, J. J. (2010). Interpretation of random effects meta-analyses. *British Medical Journal, 342*(7804). 964-967. doi: 10.1136/bmj.d549

Robertson, J., Hatton, C., Felce, D., Meek, A., Carr, D., Knapp, M., … Lowe, K. (2005). Staff stress and morale in community cased settings for people with intellectual disabilities and challenging behaviour: a brief report. *Journal of Applied Research in Intellectual Disabilities, 18*(3), 271-277. doi: 10.1111/j.1468-3148.2005.00233.x

Rose, J., Jones, F., & Fletcher, B. (1998). Investigating he relationship between staff stress and worker behaviour. *Journal of Intellectual Disability Research, 42*(Pt 2), 163-172. doi: 10.1046/j.1365-2788.1998.00115.x

Rose, J., Madurai, T., Thomas, K., Duffy, B., & Oyebode, J. (2010). Reciprocity and burnout in direct care staff. *Clinical Psychology and Psychotherapy, 17*(6), 455-462. doi: 10.1002/cpp.688

Rothstein, H., Sutton, A. J. & Borenstein, M. (2005). *Publication bias in meta-analysis: prevention, assessment and adjustments.* Chichester, England: Wiley.

Schmidt, F. L., & Hunter, J. E. (2014). *Methods of Meta-Analysis: Correcting Error and Bias in Research Findings* (3rd ed.). Thousand Oaks, CA: Sage.

Schuengel, C., Kef, S., Damen, S., & Worm, M. (2010). People who need people: Attachment and professional caregiving. *Journal of Intellectual Disability Research, 54*(s1), 38-47. doi: 10.1111/j.1365-2788.2009.01236.x

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2002). *Mindfulness-based cognitive therapy for depression: a new approach to preventing relapse.* New York: Guilford Press.

Sharpley, C. F., Bitska, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability, 22*(1), 19-28. doi: 10.1080/13668259700033261

Singer, G. H., Ethridge, B. L., & Aldana, S. I. (2007). Primary and Secondary Effects of Parenting and Stress Management Interventions for Parents of Children with Developmental Disabilities: A Meta-analysis. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 357-369. doi: 10.1002/mrdd.20175

*Singh, N. N., Lancioni, G. E., Karazsia, B. T., Chan, J., & Winton, A. S. W. (2016a). Effectiveness of Caregiver Training in Mindfulness-Based Positive Behaviour Support (MBPBS) vs. Training-as-Usual (TAU): A Randomised Controlled Trial. *Frontiers in Psychology, 7*(1549). doi: 10.3389/fpsyg.2016.01549

*Singh, N. N., Lancioni, G. E., Karazsia, B. T., & Myers, R. E. (2016b). caregiver Training in Mindfulness-Based Positive Behaviour Supports (MBPBS): Effects on Caregivers and Adults with Intellectual and Developmental Disabilities. *Frontiers in Psychology, 7*(98). doi: 10.3389/fpsyg.2016.00098.

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, A. N. A., Adkins, A. D. A., & Singh, J. (2009). Mindful staff can reduce the use of physical restraints when providing care

to individuals with intellectual disabilities. *Journal or Applied Research in Intellectual Disabilities, 22*(2), 194-202. doi: 10.1111/j.1468-3148.2008.00488.x

Solomon, R., Necheles, J., Ferch, C., & Bruckman, D. (2007). Pilot Study of a Parent Training Program for Young Children with Autism. *Autism, 11*(3), 205-224. doi: 10.1177/1362361307076842

Sterne, J. A. C., Sutton, A. J., Ioannidis, J. P. A., Terrin, N., Jones, D. R., Lau, J., … Higgins, J. P. T. (2011). Recommendations for examining and interpreting funnel plot asymmetry in meta-analyses of randomised controlled trials. *British Medical Journal, 343*(d4002). doi: 10.1136/bmj.d4002

Teasdale, J. D., Segal, Z., & Williams, J. M. (1995). How does cognitive therapy prevent depressive relapse and why should attention control (mindfulness) training help? *Behavioural Research and Therapy, 33*(1), 25-39. doi: 10.1016/0005-7967(94)E0011-7

Viechtbauer, W. (2010). Conducting meta-analyses in R with the metaphor package. *Journal of Statistical Software, 36*(3), 1-48. doi: 10.18637/jss.v036.i03

Vollestad, J., Nielsen, M., & Nielson, G. (2012), Mindfulness- and acceptance-based interventions for anxiety disorders: A systematic review and meta-analysis. *British Journal of Clinical Psychology, 51*(3), 239-260. doi: 10.111/j.2044-8260.2011.020

Wendt, O., & Miller, B. (2012). Quality appraisal of single-subject experimental designs: an overview and comparison of different appraisal tools. *Education and Treatment of Children, 35*, 235-268. doi: 10.1353/etc.2012.0010

White, P., Edwards, N., & Townsend-White, C. (2006). Stress and burnout amongst professional carers of people with intellectual disability: Another health inequality.

Current Opinion in Psychiatry, 19(5), 502-507. doi:

10.1097/01.yco.0000238478.04400.e0

White, C., Holland, E., Marsland, D. & Oakes, P. (2003). The identification of environment

and cultures that promote the abuse of people with intellectual disabilities: a review of

the literature. *Journal of Applied Research in Intellectual Disabilities, 16*(1), 1-9. doi:

10.1046/j.1468-3148.2003.00147.x

Chapter 2

Empirical Paper

"It's been like a big rollercoaster … it's made my life better": What do people with an intellectual disability think about adapted Dialectical Behaviour Therapy?

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Abstract

Despite significant need, there is a lack of empirical evidence exploring the efficacy of psychological interventions for individuals with intellectual disabilities (ID). This study explored service user experiences of adapted Dialectical Behaviour Therapy (DBT) within adult community ID services. Semi-structured interviews with six participants were analysed using interpretative phenomenological analysis (IPA). Four superordinate themes emerged from the data: the impact of ID on therapy; adapting therapy; the process of group learning; and, personal growth. These inter-related themes conceptualised participants' experiences of adapted DBT as a concurrent experience of challenge and reward. The findings contribute to the growing literature supporting the efficacy of psychological therapies for people with ID, and indicate that when presented in an accessible format, adults with ID can benefit from DBT in the intended way. The findings highlight important implications for clinical practice and worthy areas of future research.

Background

Individuals with an Intellectual Disability (ID) constitute one of the most socially excluded and marginalised populations within society (Ali et al., 2012) and frequently contend acts of discrimination, prejudice and stigmatisation (Idusohan-Moizer et al., 2015). It may therefore, be somewhat unsurprising that such individuals experience significantly elevated levels of mental health difficulties in comparison to the general population (Cooper et al., 2015). The risk of mental health difficulties for individuals with ID is thought to be fourfold that of those without an ID (APA, 2013), with prevalence rates estimated between 30% and 50% (Smiley, 2005; Cooper et al., 2007). Individuals with ID therefore undoubtedly present with significant mental health needs, and, like any other population, require equitable access to a full range of psychological interventions (Irvine and Beail, 2016). Regrettably, this has not typically been the case, and historically people with ID have been "overlooked or actively excluded" from accessing psychological interventions (Banks, 2006: p.363). Fortunately, this has been challenged over recent years, and the need for services to be adapted to effectively meet the mental health needs of people with ID is now enshrined in public policy (Department of Health, 2010; 2014).

Whilst some individuals with an ID may benefit from mainstream therapeutic approaches, cognitive deficits associated with ID may prevent meaningful engagement with some standard psychological interventions (Lindsay et al., 2013). Albeit limited, emerging evidence suggests that reasonable adaptations to the delivery of standard psychological interventions can overcome such difficulties, enhancing accessibility and improving therapeutic outcomes for individuals with ID (Brown et al., 2011; Osugo and Cooper, 2016). Preliminary findings have shown promise for the use of adapted Cognitive Behavioural Therapy (CBT; Jennings and Hewitt, 2015), mindfulness (Singh et al., 2013) and psychodynamic therapies (James and Stacey, 2014). However, despite these advancements, a

lack of robust empirical evidence remains regarding the effectiveness of psychological interventions for individuals with ID (Osugo and Cooper, 2016).

Dialectical Behaviour Therapy (DBT)

Recent advancements in psychological therapy have seen the development of the 'third-wave' therapies; a modern generation of behavioural therapies including DBT (Linehan, 1993a), Acceptance and Commitment Therapy (ACT; Hayes et al., 2011) and Compassion Focused Therapy (CFT; Gilbert, 2009). DBT is a therapeutic model initially developed for individuals with a diagnosis of Borderline Personality Disorder (BPD) who present with difficult to manage, high-risk, suicidal behaviours (Dimeff and Linehan, 2001). Its integrative approach combines basic principles of behaviour therapy with eastern mindfulness practices, and is characterised by an overarching philosophy of 'dialectics'; the synthesis of opposites. DBT comprises a highly structured multi-modal approach and in standard community settings includes weekly individual therapy sessions (for motivational issues/skill strengthening), skills group (for skill development) and the availability of telephone coaching between sessions (to aid generalisation) (Linehan, 1993b). The skills group teaches skills across four key modules; emotion regulation, distress tolerance, interpersonal effectiveness and mindfulness – domains in which individuals with BPD are assumed to lack important abilities (Linehan, 2015).

DBT is now a well-established intervention, with a robust evidence-base for its efficacy in improving outcomes for individuals with BPD (see Stoffers et al., 2012; Panos et al., 2014 for reviews). As such, DBT is recommended by the National Institute for Health and Care Excellence (NICE) for women with BPD and recurrent self-harming behaviours (NICE, 2009).

Research has also highlighted the efficacy of modifying DBT for other clinical presentations, including; anorexia nervosa (Chen et al., 2015); ADHD (Fleming et al., 2015);

Autism Spectrum Disorder (ASD; Hartmann et al., 2012); depression (Harley et al., 2008) and individuals who abuse substances (Dimeff and Linehan, 2008).

DBT and people with ID

It is recommended that individuals with mild ID who present with BPD access the same interventions as others with BPD (NICE, 2009). Whilst this is true, careful attention needs to be paid to the accessibility of DBT for adults with ID. In practice, DBT can be cognitively demanding due to its complex framework and reliance upon written handouts, mnemonics and individuals providing written feedback in diary cards (Lippold, 2016); meaning that some adaptations will likely be necessary for it to be accessible for people with ID. It is important however, when making such adaptations that core DBT principles are upheld, to ensure fidelity of the model.

Although challenging, the elevated levels of mental health difficulties among individuals with ID renders it a necessity to make such adaptations and ensure that such individuals are not denied access to appropriate psychological interventions. Although the diagnosis of personality disorders in people with an ID is an issue fraught with contention (Alexander and Cooray, 2003) with true prevalence rates unknown (Moreland et al., 2008), there remains good reason for considering the use of DBT among this population. For example, Lew et al. (2006) highlight that individuals with ID are extremely likely to present with significant difficulty regulating emotions and interpersonal relationships given the pronounced experiences of invalidation throughout their lives, coupled with potential biological vulnerabilities (Linehan, 1993a). Additionally, people with an ID are at a higher risk of demonstrating challenging behaviours; for which emotional dysregulation has been considered a key contributing factor (Brown et al. 2013). Thus, as an intervention that focuses on building

self-regulation skills, DBT may be an extremely appropriate and effective intervention among this population.

Whilst the literature pertaining to the use of DBT among adults with ID remains in its infancy, preliminary findings show promise. Studies have demonstrated reductions in aggression (Hall et al., 2013), risk-taking behaviour (Lew et al., 2006) and challenging behaviours (Brown et al., 2013), as well as improved overall functioning among offenders (Sakdalan et al., 2010) and adolescents (Charlton and Dykstra, 2011). Benefits have also been demonstrated across a range of settings, including high secure (Morrissey and Ingamells, 2011) and community services (Baillie and Slater, 2014). A recent review concluded that whilst these are promising developments, there is insufficient evidence to draw firm conclusions regarding the efficacy of DBT for people with ID (McNair et al., 2016).

Understanding the ways in which psychological interventions are perceived by service users provides valuable insights into how therapeutic outcomes can be influenced by personal experience (Gordon, 2000; Elliott, 2008); thus offering important theoretical and clinical implications. To date, four studies have employed qualitative methodology to explore the experiences of adapted DBT from the perspectives of service users within ID services. Such studies have reported main themes such as; varying levels of understanding of DBT where individuals discussed personal understandings of the model (Roscoe et al., 2016); using DBT, including drawing upon support from others (Thomson and Johnson, 2017) and DBT as helpful and beneficial (Hall et al., 2013; Johnson and Thomson, 2016; Roscoe et al., 2016). However, three of these four studies focused on programmes delivered within an inpatient setting (Johnson and Thomson, 2016; Roscoe et al., 2016; Thomson and Johnson, 2017), which are likely to be inherently different from community-based programmes.

Aims

This study aims to explore service users' experiences of adapted DBT programmes within community ID services. The study aims to highlight important clinical and theoretical implications to augment future interventions and enhance efficacy and therapeutic outcomes.

2. Method

Study Design

The current paper adopted a qualitative approach to explore service users' experiences of adapted DBT. Specifically, Interpretative Phenomenological Analysis (IPA) was selected given its focus on facilitating detailed exploration of individual's experiences (Pietkiewicz and Smith, 2012).

IPA is informed by the fundamental principles of three key philosophical areas; phenomenology, hermeneutics and idiography (Larkin & Thompson, 2011). Phenomenology refers to the detailed study of conscious experience, and here focuses on how individuals perceive and discuss their DBT experience. Hermeneutics is the study of interpretation, and refers to the active role of the researcher in the interpretative process. In IPA the researcher attempts to understand the participants' experience using their own interpretation, which, IPA recognises, is shaped by their own experiences and pre-conceptions. Smith et al. (2012) refers to this fundamental process as 'double hermeneutic'; as the researcher tries "to make sense of the participant trying to make sense of what is happening to them" (p. 3). Finally, IPA draws upon the principle of idiography; the study of the particular. Here, this refers to detailed, in-depth analysis of the unique experiences of each participant, opposed to studying the probability of occurrences among larger groups and populations (Pietkiewicz and Smith, 2012). As such, IPA typically utilises small, purposively-selected, homogenous samples, who

have a particular shared experience. This facilitates rich insights into particular perspectives which offers valuable contributions to theory and clinical practice (Smith et al., 2012).

Ethical considerations

Ethical approval was granted by Bangor University School of Psychology Ethics Committee, the local NHS Research Ethics Committee and Betsi Cadwaladr University Health Board Research and Development Department.

Participants

In line with IPA, a small purposive sample was selected, consisting of six service users who had attended adapted DBT programmes within community adult ID services across North Wales. To obtain a relatively homogenous sample, service users were required to meet the following criteria: (1) diagnosed as having an ID, (2) 18+ years, (3) currently attending, or finished within the last 12 months, full programme DBT (skills group plus individual sessions), (4) been attending DBT for a minimum of 2 months, (5) participants were required to demonstrate the capacity to provide informed consent.

In total, ten individuals expressed an interest in the research, however one did not meet eligibility criteria, another opted in and then decided not to take part and two expressed interest when data collection had ceased. The final sample consisted of three male and three female service users, aged between 23 and 54 ($M = 36$ years; SD = 11.56 years). All participants were currently attending DBT; the length of time engaged varied from seven to thirty-six months ($M = 18.3$ months; SD = 10.4). All participants had been assessed as having an ID, and all had a documented history of significant difficulty regulating emotions and/or interpersonal relationships. Participant demographics are outlined in Table 1. To uphold confidentiality, participants have been ascribed pseudonyms and length of time in DBT has been provided as a range.

Participants were engaging with one of four DBT programmes across North Wales. Each programme had its own multi-disciplinary DBT consult, which was led by Clinical Psychologists all from one adult ID Clinical Psychology team. All DBT consult members had been trained by the British Isles DBT Training team. Each programme followed Linehan's (2015) Skills Training Manual, however material was adapted within each group by the respective consult to enhance accessibility. All DBT consults met bi-annually to discuss materials and adaptations to achieve as consistent approach as possible across groups.

Table 1. Participant demographics

Participant number	Participant*	Age	Diagnoses	Current/previous DBT attendee	Length of time in DBT
1	Rachel	37	Mild ID	Current	12+ months
2	Tom	43	Mild ID	Current	12+ months
3	William	54	Mild ID	Current	6-12 months
4	Becky	34	Mild ID	Current	12+ months
5	Alfie	25	Mild ID	Current	12+ months
6	Natalie	23	Mild ID	Current	6-12 months

Pseudonyms

Recruitment

Participants were recruited from NHS community ID teams across North Wales. The rationale and aims of the research were discussed at DBT consult meetings and clinicians were encouraged to approach eligible service users. Research packs were left with DBT clinicians which included an information sheet for clinicians and a participant information sheet/opt in form. Potential participants were approached by their DBT therapist, who discussed the research and participant information sheet with them. Clinicians ascertained whether the

individuals were happy to be contacted by the primary researcher; those who were completed and returned an opt-in form, on receipt of which the primary researcher contacted the individual and arranged to meet.

During the initial meeting, participants read through the participant information sheet with the researcher and asked any questions. Before continuing, capacity to provide informed consent was assessed by the researcher following a protocol based on Arscott et al. (1998). Once assessed as having capacity to provide consent, written informed consent was obtained from those willing to participate and the interview was arranged. Participants could have a carer/support present throughout the interview, however no participants opted to do so.

Data collection

Individual semi-structured interviews were conducted over a four-month period by the primary researcher. A semi-structured interview format enabled participants to give a detailed account of their experience, whilst also allowing the researcher to facilitate further reflections. As recommended by Smith and Osborn (2015) an interview schedule guided the interviews; this was developed in collaboration with the research team and focused on experiences of attending DBT and understanding of DBT concepts. Interviews took place at participants' homes or a local clinic and were conducted in English. Before beginning, participants were reminded of the research rationale and given the opportunity to ask questions. At each stage of recruitment participants were reminded of their right to withdraw at any time, and of the limits of confidentiality. Participants were encouraged to ask the researcher to clarify questions they were unsure of, and were reminded they could decline to answer questions if they wished. With participants' consent, interviews were audio-recorded and lasted between 43 and 73 minutes (M = 51.8 minutes, SD = 11.8 minutes).

At the end of the interview participants were thanked for their time and debriefed; the researcher reiterated the purpose of the research and ensured that participants were not distressed. Participants were given the option to receive a summary of the findings upon completion of the study.

As recommended by a number of authors (e.g. Fade, 2004; Elliott and Timulak, 2005) field notes were made by the researcher during each interview to aid the initial coding; these included observations of non-verbal communication, environmental factors and behaviours which were unlikely to be captured by the audio-recordings (Sutton and Austin, 2015). The researcher's reflections of the interview were also documented. Verbatim transcriptions of each interview were produced sequentially by the primary researcher; transcriptions included all spoken words, laughter, pauses, hesitations and other notable verbal qualities. To ensure anonymity, any potentially identifying information was removed and all names were replaced with pseudonyms.

Data analysis

Data was analysed sequentially by the primary researcher, following the process described by Smith et al. (2015). Initially, each transcript was read and re-read, to gain familiarity with, and become immersed in the data. Subsequently each transcript was analysed line-by-line, with exploratory descriptive, linguistic and conceptual comments being noted; this provided initial insights into the ways each participant perceived and experienced DBT and enabled more abstract concepts to be identified. Exploratory comments and concepts were then reviewed, enabling the identification of emergent themes reflective of each participant's experience; patterns and connections among the emergent themes were explored, and similar themes were grouped together. This process was repeated with each transcript. A summary table of emergent themes was developed for each transcript; all themes were supported with

verbatim quotes. The final stage of analysis involved identifying commonalities and divergences across transcripts, enabling overarching super-ordinate and sub-ordinate themes to be created. Transcripts, super-ordinate and sub-ordinate themes were reviewed by the co-authors (who were not involved in the transcription and analysis) to ensure that the findings were relevant and grounded in the data.

3. Results

From the IPA four superordinate themes emerged, each with embedded subordinate themes; (1) The impact of ID on therapy; (2) Adapting therapy; (3) The process of group learning; (4) Personal growth. The themes are outlined in Table 2 and are described in turn below.

Table 2. *Summary of superordinate and subordinate themes*

Superordinate theme	Subordinate Themes
The impact of ID on therapy	Limited comprehension.
	DBT with a big "B".
Adapting therapy	Adaptations to delivery.
	Carer involvement.
The process of group learning	Social connectedness.
	A platform of exposure.
	Individual sessions.
Personal growth	Enriched sense of self
	Reduced distress.
	Increased resilience.

The superordinate themes are a dynamic network of interrelated experiences which represent the concurrent challenging and rewarding nature of participants' therapeutic journeys. The

themes are presented as narrative accounts and are evidenced by verbatim interview extracts[3].

The following transcription conventions are used:

(…)   Words omitted to shorten quote

…   Short pause

[text]   Explanatory information provided by authors

Superordinate theme 1: The impact of ID on therapy.

All participants expressed that their learning was limited by specific impairments associated with ID such as; being *"slow at learning"*, finding it *"hard to remember"* and *"very hard to understand"* information, as well as having poor literacy skills. This theme relates to how these specific impairments impacted on the therapeutic process; often making it *"very hard work"* for participants.

Theme 1: "That part I doesn't understand": Limited comprehension. Participants used phrases such as *"coping with strong feelings", "controlling their temper"* and *"managing my anger"*. The words 'coping', 'controlling' and 'managing' indicated that participants understood that the rationale of DBT is to increase ability to cope with challenge, rather than avoid or change it.

However, with regard to abstract concepts such as mindfulness and different mind states, participants' understanding was far less robust. Participants could recall the names of some concepts, but struggled to fully comprehend them, particularly when they had no physical or concrete existence. For example, Becky recalled 'wise mind'[4] as:

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[3] To comply with NWCPP guidance, lengthier quotes have been included in a suitable tabular format within the body of the text. These tables have been numbered from 3- 23.

[4] A mind state which is a balance of logical thinking and emotional thinking.

> *Where you're thinking properly (…) it means that you thinking*
> *sensibly and you're an you talk respectfully and be respectful of*
> *one another.*

Table 3.

Becky acknowledges that wise mind involves logical or rational thinking, but does not recognise that this is balanced with emotion. Becky's understanding is that wise mind is the 'correct way' of thinking, which makes it difficult for her to appreciate that there may be times where it is appropriate and helpful to be driven by emotions. Additionally, the difficulty of abstract concepts is highlighted by Becky's attempts to make 'wise mind' more concrete by drawing upon physical examples. However, despite these difficulties, most participants did gain a partial understanding of the basic meaning of abstract ideas. For example:

> *William:*   *They were talking about erm hot mind, er erm*
> *Interviewer*:   *What's hot mind?*
> *William*:   *Yeah er, where people get boiled*
> *Interviewer*:   *People get boiled?*
> *William*:   *Yeah boiled and get red hot in their mind*
> *Interviewer:*   *Red hot in their mind, what might somebody be*
>   *like if they were in hot mind?*
> *William*:   *Angry and shout*

Table 4.

Here, William describes how 'hot mind'[5] is characterised by becoming overwhelmed by emotion; William uses the descriptions "boiled" and "red hot" to portray the intense physiological arousal one might feel when in hot mind, and indicates how this can lead to one

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[5] A state of mind in which an emotional state completely controls thinking and behaviour (known formally in DBT as emotional mind).

acting in line with their emotions. Albeit slightly distorted, William had derived a personal understanding of 'hot mind' which bears a resemblance of the true meaning.

Additionally, most participants were confidently able to recall and comprehend the concrete process of implementing a skill, but lacked understanding of *how/why* the skill worked. For example, Tom explained:

Tom:	*You touch something cold if I remember (…) yeah put a couple of ice cubes in your hand*
Interviewer:	*Why did you have to do that?*
Tom:	*Oh, I, I can't remember now*

Table 5.

This infers that participants had a firm understanding of the process of implementing a skill, but lacked awareness of the reasoning behind it.

Theme 2: DBT with a big "B". Despite being challenging to apply, all participants could implement skills in a variety of settings such as *"in college or work", "in the house", "shopping"* and *"on the bus"*. This integration suggested that participants had developed enhanced insight of emotions and increased ability to recognise when and how to implement skills. However, a striking observation was that every participant expressed a tendency to adopt more behaviourally-based skills; indicating an increased confidence in utilising skills that required an act of doing rather than cognitive processes. For example, Rachel would *"go for a walk"* when she felt angry and Tom 'sat on his hands' to prevent him lashing out. Similarly, Alfie described:

Doing a bit of calm breathing if I'm feeling like very stressed or something and using a bit of like cold, like dabbing a bit of cold water on me face an that and then going up and down the stairs.

Table 6.

The complete absence of more cognitive skills (e.g. negotiation/problem solving) in participants' examples of utilising skills indicated that participants were more able, and more confident, implementing skills with explicit, concrete instructions and visible actions rather than abstract skills involving verbal reasoning. This suggests that concrete skills were easier for participants to master, possibly because they could be rote learned as they involve the exact same process and look identical each time it is applied, making repetition easier. Participants did not utilise more cognitive skills based on judgement and reasoning processes; seemingly due to these feeling more confusing and ambiguous. For example, William appeared much less clear about how to practise mindfulness *"going outside and thinking about something else in your mind"*[6]*,* compared to deep breathing; *"take three deep breaths in and breathe out 1, 2, 3, 4, 5".*

Superordinate theme 2: Adapting therapy.

This theme follows the previous theme, and relates to overcoming the challenges posed by the specific impairments associated with ID. All participants highlighted the need for specific adaptations to be made to the delivery of material for it to be accessible and meaningful; *"they word it a different way now [which makes understanding easier]".* However, participants also highlighted how some adaptations, considered useful by facilitators, could be unhelpful for their personal development, such as the presence of carers/support in group.

Theme 1: Adaptations to delivery. All participants expressed that the delivery and presentation of information was key; highlighting specific factors that promoted and inhibited their learning. For the majority, rehearsal was vital in strengthening retention and solidification of information.

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[6] Conventional mindfulness practice involves 'paying attention in a particular way: on purpose, in the present moment, and non-judgementally' (Kabat-Zinn, 1994, p. 4)

> *Natalie:* We go over it again every time (...) before we do the
> new stuff (...) then it brings our minds back to that (...)
> so we remember better.

<div align="right">Table 7.</div>

Natalie indicated that one session on each skill (as is typically the case) is insufficient, and that devoting additional time to recapping previous material is crucial before the introduction of new information; otherwise information is lost and learning does not occur. Likewise, half of the participants highlighted the importance of pace, stating that *"to slow down"* and *"explaining slowwwly"* was helpful. Becky indicated that information presented in quick succession is too difficult to process which inhibits learning: *"sometimes it's going too fast and I couldn't keep on"*.

The majority of participants also spoke of how a more interactive approach, including *"taking part"* and *"less words and work"*, was more meaningful and effective. This likely reflected poor literacy skills, often characteristic of individuals with ID, which mean discussion and physical practise are more valuable. William highlighted that the physical demonstration and modelling of skills held more resonance for him, and enabled him to gain a better understanding of utilising tone when expressing himself.

> *William:* When things are not going right and people getting
> anxious say 'excuse me why are you late or like that'
> (...) negative say (...) **'it's no use to be late like that!'**
> just just acting like a play.
>
> *Interviewer:* Oh so you act things out like a play?
>
> *William:* Yeah yeah, like negative things and an positive things
> as well.
>
> *Interviewer:* (...) are they helpful?

<div align="right">63</div>

> *William: Well they help me in that way as well.*

<div align="right">Table 8.</div>

The majority of participants also noted difficulties associated with language, expressing that *"pictures"* and concrete language (e.g. *"breathe out 1, 2, 3, 4, 5"*) promoted learning and understanding. The ideas communicated above therefore indicate the necessity of understanding the impairments associated with ID which limit learning, and modify materials appropriately to support learning.

>   ***Theme 2: Carer involvement.*** One adaptation made across all groups was the presence of carers/support in the skills group to aid learning. However, in relation to involving carers within the DBT process, participants were presented with a dilemma based on conflicting interests. All participants noted that it was helpful for their carers to be involved in DBT, as they developed a sound knowledge of skills which enabled them to prompt participants to utilise their skills in their daily lives:

> *Alfie: Yeah, they [staff] know about it [DBT] yeah. Which is good*
> *really, because then sometimes the, if they know that I'm*
> *about to lose my temper they can tell me some things what*
> *they know help me.*

<div align="right">Table 9.</div>

Thus, indicating the crucial role of carers in skill consolidation and generalisation, rendering their presence at skills group crucial for them to obtain knowledge of DBT skills. However, all but one participant disliked being supported at group and *"preferred it to go on [their] own"* as support hindered their independence and opportunity to connect with others. Alfie attended group alone, and believed that he *"wouldn't most probably been speaking to [his] friends"* if he had been supported to group, and Rachel felt she could talk more openly without her carers present: *"You can talk without your carers being there, or your parents which is better"*. Thus,

carer involvement was a contentious issue, and seemingly conceptualised by service users as a duality of facilitating growth and limiting self-development.

Superordinate theme 3: The process of group learning.

This superordinate theme concerns participants' direct experience of engaging with adapted DBT. Whilst all participants acknowledged the simultaneous modes of therapy (individual and group sessions); they mostly spoke about the group process, seemingly because the group environment was more emotionally salient for participants. All participants described powerful emotional responses evoked by group participation such as feeling *"so excited"* or finding it *"nerve wracking".*

> ***Theme 1: "It feels like it's a family": Social connectedness.*** Despite initial anxiety, all participants took great pleasure from being part of a group and viewed the skills group as a social opportunity. For all participants, the group facilitated the development of valued social relationships:

Alfie:	*It's just very enjoyable and I just liked having company (...) I made new friends.*
Natalie:	*When we have cup of teas yeah it's good because we all get to chat together.*

Table 10.

Alfie's use of the word 'company' highlighted how engagement within the group reduced feelings of loneliness and Natalie indicated how chatting 'together' fostered a sense of unity and belonging. Rachel *"loved"* attending group, indicating that she relished the opportunity to interact with other like-minded individuals and thrived off building meaningful interpersonal relationships; something which William inferred was otherwise virtually non-existent in his typical day-to-day life:

> *Part of the group, yeah it's good, well just, see more, see*
> *people yeah cos' last time I mixed with other people was about*
> *22 years ago.*

<div align="right">Table 11.</div>

This illustrates the heightened exclusion and loneliness commonly experienced by individuals with ID, and highlights how the socially inclusive atmosphere within the group represented a stark contrast to their usual experience. The social opportunity provided by the group may therefore have been a unique opportunity for many; offering an understanding of why the sense of social inclusion was experienced so powerfully and welcomed greatly by participants.

Further to feeling included and *"part of it"*, all participants also identified the act of engaging with others as validating, and described how discovering that their difficulties were similar to others fostered a sense of self-acceptance:

> *Natalie:* *I felt really, good in myself, because everyone had*
> *problems too.*
>
> *Becky:* *It's helped me to realise that there are other*
> *people out there who have problems like me too*

<div align="right">Table 12.</div>

Through sharing experiences, participants came to understand that their "problems", which they believed to be abnormal and indicative of their defectiveness, were actually common and shared by others, which reduced feelings of shame and alienation. Furthermore, all participants recognised the value of drawing upon these shared experiences to *"learn from each other"*.

> *Natalie:* *You can tell people your problems to people and people*
> *tell their problems to you and you can help each other,*
> *they get through it eventually.*

<div align="right">Table 13.</div>

Participants thrived off the reciprocity of peer support; they felt reassured, comforted and valued by the perceived respect and empathy received from others, and were left feeling empowered and better able to manage their difficulties; *"they helped my problems as well"* and *"it helps you keep you positive doesn't it"*. Additionally, offering support to peers boosted participants' confidence and self-esteem, fostering a sense of positivity and optimism, enhancing overall levels of happiness. For Tom, *"keeping in touch"* with a friend outside of group meant that this support transferred to his personal life, indicating that the group facilitated the development of a meaningful social network which provided him with companionship and a sense of purpose in his life.

Theme 2: A platform of exposure. The group setting was acknowledged by all to be challenging and exposed participants to feared situations/feelings. All participants described experiences of social anxiety from merely attending the group setting; *"I hate when you walk into a new place for once, er for the first time, people looks on you don't they. I hate that."* All participants acknowledged the existence of inevitably challenging group dynamics which elicited emotionally dysregulating states such as feeling *"stressed"* and *"anxious"*. Tom described how tension in the group left him feeling *"a bit sweaty (…) like you palm was going"*.

Natalie:	*We're either starting late or people aren't coming on time which is annoying.*
Tom:	*We got one lad he likes to fiddle with his er mobile (…) I hate that he brought the rule up, he doesn he doesn't listen to it, I hate that.*

Table 14.

All participants also expressed finding it *"tough and hard"* hearing about others' difficulties. Natalie described how empathising with participants filled her with sadness, and how not sharing the same experience left her feeling guilty and helpless.

> *Natalie:*   *It's quite difficult [when people share problems],*
> *because I feel sorry for the people then (...) this girl*
> *told me her problem (...) an I said I don't have that*
> *problem, an I felt really bad for her.*

Two participants also noted that group discussions elicited painful memories which they typically strived to avoid. For example, Becky explained: *"It just brings the horrible memories back of what happened ... and I don't want to think about it"*. However, participants appeared to accept this exposure to difficult experiences was inherent to the group process, and realised that they had little choice but to *"get on with it"*. This unavoidable exposure to dysregulating experiences provided valuable real-life opportunities for participants to continually practise and enhance their skills, such as:

> *Becky:*   *Cutting across each other when you're talking ... it was*
> *annoying yes because we're all trying to talk and then*
> *somebody's yap yap yap when you're trying to get a*
> *word in*
> *Interviewer:* *How do you manage that?*
> *Becky:*   *I just grit my teeth and get on with it.*
>
> *Interviewer:* *What do you do in group when you feel stressed?*
> *Tom:*   *Put our hand up and tell Scott* [therapist] *to*
> *ask him nicely to put the phone back into his*
> *pocket*

The group setting was interpreted to serve as a safe, non-threatening situation for participants to consolidate their skills. Rachel demonstrated how this interpersonal skill practise in group generalised as it helped her *"get on with other people"* in her daily life.

   Theme 3: Individual sessions. Participants all described relying on their individual therapy sessions to aid consolidation of skills taught in the group and integrate them into their

lives. The group provided the bare bones of skills, however participants required much more support to understand and begin practising them. Participants valued the opportunity to revisit material to enhance retention; *"Amy [therapist] helps me to remember"*, and appreciated being able to *"work on it together"* to help embed skills into their daily life:

Becky:	*She helps me to think about how I can do things to help, like if I feel that an argument is gonna' happen, I take myself to another room.*

Table 17.

Individual sessions were also a safe space which was more *"personal"* and thus more meaningful for participants. Participants appreciated their therapist focusing on concrete examples of their personal difficulties, and adopting a scaffolding process to help them apply skills in their daily life.

William:	*She [therapist] told me to, it, say if the bus doesn't come and you get upset (...) just got to breathe in deep and breathe out 1, 2, 3, 4, 5.*

Table 18.

Individual sessions were thus interpreted as a crucial element and as the key catalyst for change; without which generalisation of skills would have been less achievable.

Superordinate theme 4: Personal growth.

Despite all participants feeling that the process was onerous, with progress being slow and non-linear; *"like a rollercoaster"*, every participant asserted extreme gratitude for DBT, expressing that their challenging journey had been worthwhile: *"I'm glad I sticked to it, I am, I'm very glad. It's helped me a long way"*. All participants referenced positive changes which had occurred in their lives since engaging with DBT, and reflected upon the difference between how they felt prior to starting DBT and the time of the interview; *"it's not anywhere as bad as*

before". All participants spoke of *"lots"* of *"different"* benefits, acknowledging the expansive nature of DBT.

Theme 1: "It's helped me become a better person": Enriched sense of self. All participants referred to a sense of accomplishment and personal growth, which was interpreted as being way above and beyond reduced distress and increased ability to cope outlined below. Participants talked of feeling "*really proud*" and *"over the moon"*, indicating a deep sense of pleasure and satisfaction regarding their achievements. Some participants expressed a sense of disbelief; as though they never dreamed they had the ability to make such meaningful and positive progress:

> *Rachel: I can't believe that I'm sat here three years afterwards, and can talk to somebody how I'm actually feeling ... and that I can actually talk.*
>
> *Table 19.*

Alfie indicated that for him the sense of achievement was astonishing and left him overwhelmed with joy:

> *Alfie: When I got my certificate I just nearly broke down (...) I nearly broke down in tears (...) when I first started I was like argh I'm not going to be able to do this, but once I got my certificate I just aww I just was over the moon I was.*
>
> Table 20.

A sense of real enriched self-concept was interpreted across the transcripts, with all participants alluding to heightened self-efficacy and self-esteem; *"I feel more confident"; "I'm just really proud of myself for actually doing it"*. As indicated by Becky, participants appeared much more compassionate towards themselves and generally held themselves in higher regard; thus, fostering feelings of happiness, satisfaction and greater self-worth:

> *Becky: Helps me realise that I'm a good person, that I've come this*
> *far and, nothing's gonna' get in my way*

Theme 2: "I'm just less erm, not as stressed and down": Reduced distress. DBT was interpreted as a liberating process; with all participants voicing how helpful it was in reducing symptoms of mental health difficulties and alleviating emotional distress. Rachel *"didn't feel half as bad"* as she previously did, while Natalie felt that DBT made her anxiety and depression much *"less"*; inferring that engaging in DBT had helped lift a weight from their shoulders and allowed them to feel freer of suffering. For William, DBT appeared to be a tool which he perceived helped physically remove unwanted emotions that were trapped inside him:

> *It helps to get my anxious, anxious and frustrated out (…) helped me*
> *to get anxious out.*

It was interpreted that by reducing anguish DBT enabled participants to discover a sense of inner peace and contentment; subsequently improving overall levels of happiness and emotional wellbeing leaving them *"more calm"* and *"settled"*.

Theme 3: "I can cope with things now": Increased resilience. Participants felt stronger, more in control and better able to effectively manage daily stress. Participants spoke of having greater insight into their emotions; *"helped me understand my feelings",* and an increased ability to regulate emotions and manage difficulty; *"I cope better now with tricky situations"*. Participants gave numerous examples demonstrating an increased capacity to effectively manage discomfort and adapt to challenge:

> *Rachel: Say we had an argument here, I would have been able to*
> *cope with it, better than I did, before I would of ran out*
> *the door.*

> *Tom:* It's helped me a lot with my temper (…) before that I would
> of clacked him one (…) now I wouldn't.

Table 22.

Participants also had enhanced communication skills, enabling them to better interact with others. As such, all participants described having healthier interpersonal relationships with those around them, fostering positive feelings of acceptance and self-worth.

> *Alfie:* I don't argue with staff or with other residents type thing.
>
> *Natalie:* Me and my partner are working a a lot better
>
> *Becky:* It's helped me become a better person (…) just better than I
> was before. Nicer.

Table 23.

4. Discussion

The four superordinate themes conceptualised participants' experiences of adapted DBT as a concurrent experience of challenge and reward. The impact of ID on ability to learn was acknowledged by all, and all participants highlighted adaptations were necessary to accommodate their needs and support learning. The challenging and emotive nature of the group meant that it held more significance for participants than other elements of the therapy. Engagement in the group facilitated the development of crucial skills through exposure to challenging situations, as well as serving as an opportunity for participants to develop a unique sense of connectedness. Despite being a challenging process, all participants reflected upon positive changes that DBT had engendered in their lives, including; enriched self-worth, increased resilience and reduced distress. The present study adds to the growing literature relating to the effectiveness of psychological therapies for people with ID; the findings provide

crucial insights into the therapeutic journey of adapted DBT for service users and highlight significant implications for clinical practice.

Many of the themes are consistent with existing literature. For example, findings consistently report positive outcomes following DBT, such as increased resilience, reduced maladaptive behaviours, increased control and improved interpersonal relationships; this holds true for participants both with (Hall et al., 2013; Roscoe et al., 2016) and without an ID (Katsakou et al., 2012; McSherry et al., 2012). This is an important finding which supports that when presented in an accessible format, people with an ID can benefit from DBT in the intended way, similarly to the general population.

Additionally, the findings echo those in the existing literature which highlight that important therapeutic gains such as acceptance, value and belonging arise through the DBT group process; again resembling the experience of participants both with (Hall et al., 2013; Roscoe et al., 2016) and without an ID (Hodgetts et al., 2007; McSherry et al., 2012). This phenomenon is also widely observed among other clinical populations (e.g. psychosis; Newton et al., 2007) and psychological therapies (e.g. CFT; Heriot-Maitland et al., 2014), and is consistent with theories of group therapy which suggest the realisation that others share similar difficulties leads to catharsis (Yalom, 2008). Group engagement thus positively contributes to the basic human need to belong and feel accepted (Hutchinson et al., 2007); the value of which has been clearly researched and documented, along with the converse detrimental effects of belonging to a marginalised group (Tajfel and Turner, 2004; Zolkowska and Kaliszewska, 2014). The group element is thus a crucial process for individuals with ID, for whom social opportunities are often an impossibility and stigmatisation and exclusion are the norm (Hall, 2010).

In light of this, it could be inferred that much of the observed positive change emanated solely from social interaction. However, the frequent exposure to challenging situations in group which compelled the implementation and practice of skills suggested that the group also played a crucial role in skill consolidation and integration. Thus, capturing a key aim of the skills group and indicating the group process offered valuable contributions aside from the psychological gains associated with social inclusion. Together these findings highlight the skills group as a key learning experience for participants, and suggest that teaching skills on an individual basis in isolation would significantly reduce therapeutic gains.

The emergent theme which reflected participants' limited understanding of DBT concepts was consistent with existing literature from within ID services, but represented a stark contrast to findings within non-ID services, where participants demonstrate enhanced knowledge and understanding of DBT concepts (e.g. McSherry et al., 2012). This suggests that despite the adaptations, information often remained too abstract for participants to fully understand, indicating that further modification may be necessary to present information in a more concrete and accessible manner.

However, a striking finding was that despite this limited understanding, participants evidenced effectively implementing skills into their daily lives; supporting the assumption that individuals with ID can benefit from psychological principles despite being unable to fully comprehend or articulate them (Jones and Dowey, 2013). For example, many participants meaningfully engaged in mindfulness practices (e.g. mindful eating), despite being unable to articulate the concept. This is an observation that has also been previously captured in research relating to adapted DBT (Roscoe et al., 2016), mindfulness (Yildiran and Holt, 2015) and CFT groups (Clapton et al., 2017) for people with ID. Thus, in practice, focusing on experiential learning whereby people with ID can learn *what* to do without necessarily comprehending *why,* may prove to be sufficient.

Another key finding was participants' preference for behavioural-based skills. This is consistent with observations in clinical practice whereby service users are often more responsive to behavioural elements of psychological therapies (e.g. relaxation techniques), leading professionals to increase their focus on such elements (Sturmey, 2006). Additionally, it has been identified that many CBT interventions adopt a 'deficit' model, utilising educational or self-instructional type approaches, and rarely involve modifying cognitive distortions (Jahoda, 2016). DBT may therefore be a psychological therapy that lends itself more favourably to people with ID, due to the increased opportunity for experiential learning, which minimises otherwise difficult cognitive and verbal reasoning demands.

All participants acknowledged the necessity to modify the therapeutic approach to support learning. Interestingly, the specific examples highlighted as beneficial (e.g. slow pace, minimal language) married up with existing recommendations regarding ID-specific adaptations to therapy (Gore and Hastings 2016; Lindsay et al., 2013); indicating that people with ID have an awareness of how specific ID impairments impact learning. The findings also emphasise the importance of modelling and visual aids; thus, indicating that providing recorded demonstrations of skills may be a useful technique to promote consolidation.

Consistent with previous studies, findings highlighted the crucial role caregivers play in supporting skill consolidation and generalisation (Barnicot et al., 2015). However, participants also indicated that carer presence at group exerts detrimental consequences for service users. Whilst this has been previously raised as a risk by authors (Pfadt, 1991), it is a novel finding not previously highlighted by service users. This has important implications for the involvement of carers in clinical practice, and discussions with service users should be imperative to ascertain their preferences and accommodate these accordingly. Findings suggest that an optimal arrangement may be that service users and carers attend concurrent but separate groups; enabling carers to gain vital knowledge of DBT skills, whilst also promoting

independence among service users. Where limited resource may prevent this, it would be worth offering a separate workshop for carers at least once per module.

Limitations

The findings of the present study should be considered in light of a number of methodological factors. Firstly, there was variability across participant characteristics; participants ranged in age, presented with idiosyncratic difficulties, and the length of time engaged in DBT varied. All of which may have impacted upon participant levels of understanding and overall experience of DBT. These factors, which are unavoidable when conducting research in day-to-day clinical practice, ultimately reduce overall heterogeneity of the sample; a key condition of IPA.

Additionally, in the absence of a standardised adapted version of DBT for individuals with ID, each DBT consult made their own adaptations to meet the needs of their service users. These adaptations were not documented or consistent across sites. Participants were thus likely to have been subject to different experiences of adapted DBT; representing a further source of variability and posing further risk to homogeneity.

It is acknowledged that individuals with ID often provide socially desirable responses (Jobson et al., 2013). Consistent with this, there was a general lack of expressed dissatisfaction or negativity towards DBT observed throughout the transcripts, thus questioning the reliability of the interview data. This may have been additionally skewed by the lack of alternatives offered to individuals with an ID; leaving them compelled to be thankful for anything offered. Moreover, whilst the researcher adopted an exploratory approach and used open-ended questions, prompts used to follow up participant reflections may have inevitably influenced participant responses.

In line with IPAs focus on purposive samples, it is acknowledged that the study's findings are representative of a small sample of service users only. All participants had a mild ID, and possessed levels of communication and cognitive skills which enabled them to benefit from psychological interventions; thus, limiting the sample to individuals of a similar ability.

Finally, the double hermeneutic process of IPA should be borne in mind; the extracted themes are based on the primary researchers' interpretations, and whilst co-authors reviewed transcripts to ensure themes were grounded in the data, findings are representative of one interpretation opposed to a definitive truth.

Conclusions

The findings suggest that adults with ID experience adapted DBT as a concurrently challenging and rewarding experience. The findings contribute to the growing literature supporting the efficacy of psychological therapies for people with ID, and indicate that when presented in an accessible format, adults with ID benefit from DBT in the intended way, similar to the general population. The findings highlight important implications for accommodating the needs of people with ID in clinical practice. However, the evidence-base remains very much in its infancy, and more research is warranted; further research may wish to focus on understanding which components of DBT lead to change for individuals with ID, to further augment the intervention for adults with ID.

Declaration of Conflicting Interests

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References

Alexander RT, and Cooray S (2003) Diagnosis of personality disorder in learning disability. *British Journal of Psychiatry* 182(S44): 28-33. DOI: 10.1192/bjp.182.44.s28

Ali A, Hassiotis A, Stydom A, and King M (2012) Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities* 33(6): 2122-2140. DOI: 10.1016/j.ridd.2012.06.013

American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Arscott K, Dagnan D, and Kroese BS (1998) Consent to Psychological Research by People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities* 11(1): 77-83. DOI: 10.1111/j.1468-3148.1998.tb00035.x

Baillie A, and Slater S (2014) Community dialectical behaviour therapy for emotionally dysregulated adults with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities* 8(3): 165-173.

Banks R (2006). Psychotherapeutic interventions for people with learning disabilities. *Psychiatry* 5(1): 363-367. DOI: 10.1053/j.mppsy.2006.07.004

Brown JF, Brown MZ, and Dibiasio P (2013) Treating Individuals With Intellectual Disabilities and Challenging Behaviors With Adapted Dialectical Behavior Therapy. *Journal of Mental Health Research in Intellectual Disabilities* 6(4): 280-303. DOI: 10.1080/19315864.2012.700684

Brown M, Duff H, Karatzias T, and Horsburgh D (2011) A review of the literature relating to psychological interventions and people with intellectual disabilities: Issues for research, policy,

education and clinical practice. *Journal of Intellectual Disabilities* 15(1): 31-45. DOI: 10.1177/1744629511401166

Charlton M and Dykstra EJ (2011) Dialectical behaviour therapy for special populations: Treatment with adolescents and their caregivers. *Advances in Mental Health and Intellectual Disabilities* 5(5), 6-14.

Chen EY, Segal K, Weissman J, Zeffiro TA, Gallop R, Linehan MM, Bohus M, and Lynch TR (2015) Adapting Dialectical Behavior Therapy for Outpatient Adult Anorexia Nervosa – A Pilot Study. *International Journal of Eating Disorders* 48(1): 123-132.

Clapton NE, Williams J, Griffith GM, and Jones RSP (2017) 'Finding the person you really are … on the inside': Compassion focused therapy for adults with intellectual disabilities. *Journal of Intellectual Disabilities.* Epub ahead of print 18 December 2017. DOI: 10.1177/1744629516688581

Cooper S-A, McLean G, Guthrie B, McConnachie A, Mercer S, Sullivan F, and Morrison J (2015) Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Family Practice* 16(1): 110-121. DOI: 10.1186/s12875-015-0329-3

Cooper S-A, Smiley E, Morrison J, Williamson A and Allan L (2007) Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry* 190: 27-35. DOI: 10.1192/bjp.bp.106.022483

Department of Health (2010) *Valuing people now.* London: The Stationery Office.

Department of Health (2014) *Positive and safe.* London: The Stationery Office.

Dimeff LA, and Linehan MM (2001) Dialectical behavior therapy in a nutshell. *The California Psychologist* 35: 10-13.

Dimeff LA, and Linehan MM (2008) Dialectical Behavior Therapy for Substance Abusers. *Addiction Science & Clinical Practice* 4(2): 39-47.

Elliott R (2008) Research on client experience of therapy: Introduction to the special section. *Psychotherapy Research* 18: 239-242.

Elliott R, and Timulak L (2005) Descriptive interpretative approaches to qualitative research. In: Miles J and Gilbert P (eds.) *A Handbook of Research Methods for Clinical and Health Psychology.* Oxford, UK: Oxford University Press, pp. 147 – 160.

Fade S (2004) Using interpretative phenomenological analysis for public health nutrition and dietetic research: a practical guide. *Proceedings of the Nutrition Society* 63(4): 647-653. DOI: 10.1079/PNS2004398

Fleming AP, McMahon RJ, Moran LR, Pererson AP, and Dreessen A (2015) Pilot Randomized Controlled Trial of Dialectical Behaviour Therapy Group Skills Training for ADHD Among College Students. *Journal of Attention Disorders* 19(3): 260-271.

Gordon, N. S. (2000). Researching psychotherapy, the importance of the client's view: A methodological challenge. *The Qualitative Report* 4(3): 1-20

Gilbert P (2009) *The Compassionate Mind: A New Approach to Life's Challenges.* Oakland, CA: New Harbinger Publications.

Gore NJ, and Hastings RP (2016) Mindfulness and acceptance-based therapies. In: Beail N (ed.) *Psychological therapies and people who have intellectual disabilities.* Leicester: British Psychological Society, pp. 44-54.

Hall E (2010) Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research* 54(1): 48-57. DOI: 10.111/j.1365-2788.2009.01237.x

Hall L, Craven S, and Woodrow C (2013) People with learning disabilities experiences of a dialectical behaviour therapy skills group: a thematic analysis. *Clinical Psychology & People with Learning Disabilities* 11(1): 7-11.

Harley R, Sprich S, Safren S, Jacobo M, and Fava M (2008) Adaptation of Dialectical Behavior Therapy Skills Training Group for Treatment-Resistant Depression. *The Journal of Nervous and Mental Disease* 196(2): 136-143.

Hartmann K, Urbano M, Manser K, and Okwara L (2012) Modified Dialectical Behavior Therapy to Improve Emotion Regulation in Autism Spectrum Disorders In: Richardson C E and Wood R A (eds) *Autism Spectrum Disorders New Research: Neurodevelopmental diseases laboratory and clinical research.* Hauppauge, New York: Nova Science Publishers Inc., pp. 41-72.

Hayes SC, Strosahl KD, and Wilson KG (2011) *Acceptance and commitment therapy: The process and practice of mindful change.* London, UK: The Guilford Press.

Heriot-Maitland C, Vidal JB, Ball S, and Irons C (2014) A compassionate-focused therapy group approach for acute inpatients; feasibility, initial pilot outcome data, and recommendations. *British Journal of Clinical Psychology* 53(1): 78-94. DOI: 10.1111/bjc.12040

Hodgetts A, Wright J, and Gough A (2007) Clients with borderline personality disorder: Exploring their experiences of dialectical behaviour therapy. *Counselling and Psychotherapy Research* 7(3): 172-177.

Hutchinson P, Abrams D, and Christian J (2007) The Social Psychology of Exclusion. In: Abrams D, Hogg MA and Marques JM (eds.) *Social Psychology of Inclusion and Exclusion.* London, UK: Psychology Press, pp. 29-57.

Idusohan-Moizer H, Sawicka A, Dendle J, and Albany M (2015) Mindfulness-based cognitive therapy for adults with intellectual disabilities: an evaluation of the effectiveness of mindfulness in reducing symptoms of depression and anxiety. *Journal of Intellectual Disability Research* 59(2): 93-104. DOI: 10.1111/jir.12082

Irvine M, and Beail N (2016) Identifying and meeting the emotional and mental health needs of people who have intellectual disabilities through psychological therapies. In: Beail N (ed.) *Psychological therapies and people who have intellectual disabilities.* Leicester, UK: The British Psychological Society, pp. 11-19.

Jahoda A (2016) Cognitive behavioural therapy. In: Beail N (ed.) *Psychological therapies and people who have intellectual disabilities.* Leicester: British Psychological Society, pp. 29-34

James CW, and Stacey JM (2014) The effectiveness of psychodynamic interventions for people with learning disabilities: a systematic review. *Tizard Learning Disability Review* 19(1): 17-24. DOI: 10.1108/TLDR-10-2012-0009.

Jennings C, and Hewitt O (2015) The use of cognitive behaviour therapy to treat depression in people with learning disabilities: a systematic review. *Tizard Learning Disability Review* 20(2): 54-64. DOI: 10.1108/TLDR-05-2014-0013

Jobson L, Stanbury A, and Langdon PE (2013) The self-and other-deception questionnaires-intellectual disabilities (SDQ-ID and ODQ-ID): Component analysis and reliability. *Research in Developmental Disabilities* 34(10): 3576-3582. DOI: 10.1016/J.RIDD.2013.07.004

Johnson P, and Thomson M (2016) Journeys into dialectical behaviour therapy (DBT): capturing the staff and service-user experience. *Journal of Intellectual Disabilities and Offending Behaviour* 7(2): 84-93. DOI: 10.1108/JIDOB-09-2015-0027

Jones RS, and Dowey A (2013) Behavioural approaches to working with mental health problems. In: Taylor JL, Lindsay WR, Hastings RP and Hatton CS (eds). *Psychological Therapies for Adults with Intellectual Disabilities.* Chichester: John Wiley and Sons, pp. 223-235.

Kabat-Zinn J (1994) *Wherever you go, there you are: mindfulness meditation in everyday life.* New York: Hyperion.

Katsakou C, Maroughka S, Barnicot K, Savill M, White H, Lockwood K, and Priebe S (2012) Recovery in Borderline Personality Disorder (BPD): A Qualitative Study of Service Users' Perspectives. *PLoS One* 7(5): e36517. DOI: 10.1371/journal.pone.0036517

Larkin M, and Thompson AR (2011) Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In: Thompson A and Harper A (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners.* Oxford, UK: Wiley & Sons, pp. 99-116.

Lew M, Matta C, Tripp-Tebo C, and Watts, D (2006) Dialectical Behavior Therapy (DBT) for Individuals with Intellectual Disabilities: A Program Description. *Mental Health Aspects of Developmental Disabilities* 9(1): 1-12.

Lindsay WR, Jahoda AJ, Willner P, and Taylor JL (2013) Adapting psychological therapies for people with intellectual disabilities I: Assessment and cognitive deficit considerations. In: Taylor JL, Lindsay WR, Hastings RP, and Hatton C (eds.) *Psychological therapies for adults with intellectual disabilities* Chichester: Wiley-Blackwell, pp. 69-84.

Linehan, MM (1993a) *Cognitive-behavioral treatment of borderline personality disorder.* New York: The Guilford Press.

Linehan MM (1993b) Dialectical behavior therapy for treatment of borderline personality disorder: Implications for the treatment of substance abuse. *NIDA research monograph* 137: 201-216.

Linehan M (2015) *DBT Skills Training Manual, Second Edition*. New York, NY: The Guilford Press.

Lippold T (2016) Dialectical behavior therapy. In: Beail N (ed.) *Psychological therapies and people who have intellectual disabilities.* Leicester: British Psychological Society, pp. 55-60.

McNair L, Woodrow C, and Hare D (2016) Dialectical Behaviour Therapy (DBT) with People with Intellectual Disabilities: A Systematic Review and Narrative Analysis. *Journal of Applied Research in Intellectual Disabilities* 30(5): 1-18. DOI: 10.1111/jar.12277

McSherry P, O'Connor C, Hever D, and Gibbons P (2012) Service user experience of adapted dialectical behaviour therapy in a community adult mental health setting. *Journal of Mental Health* 21(6): 539-547. DOI: 10.3109/09638237.2011.651660

Moreland J, Hendy S, and Brown F (2008). The Validity of a Personality Disorder Diagnosis for People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities* 21(3): 219-226. DOI: 10.1111/j.1468-3148.2007.00399.x

Morrissey C, and Ingmells B (2011) Adapted dialectical behaviour therapy for male offenders with learning disabilities in a high secure environment: six years on. *Journal of Learning Disabilities and Offending Behaviour,* 2(1), 8-15.

National Institute for Health and Care Excellence (2009) *Borderline personality disorder (BPD) CG78.* London, UK: Author.

Newton E, Larkin M, Melhuish R, and Wykes T (2007) More than just a place to talk: Young people's experiences of group psychological therapy as an early intervention for auditory

hallucinations. *Psychology and Psychotherapy: Theory, Research and Practice* 80(Pt 1): 127-149. DOI: 10.1348/147608306X110148

Osugo M and Cooper SA (2016) Interventions for adults with mild intellectual disabilities and mental ill-health: a systematic review. *Journal of Intellectual Disability Research* 60(6), 615-622.

Panos PT, Jackson JW, Hasan O, and Panos A (2012). Meta-Analysis and Systematic Review Assessing the Efficacy of Dialectical Behavior Therapy (DBT). *Research on Social Work Practice* 24(2): 213-223. DOI: 10.1177/1049731513503047

Pietkiewicz I, and Smith JA (2012). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Psychological Journal* 18(2): 361-369. DOI: 10.14691/CPPJ.20.1.7

Pfadt A (1991) Group psychotherapy with mentally retarded adults; Issues related to design, implementation and evaluation. *Research in Developmental Disabilities, 12,* 261-285.

Roscoe P, Petalas M, Hastings R, and Thomas C (2016) Dialectical behaviour therapy in an inpatient unit for women with a learning disability: Service users' perspectives. *Journal of Intellectual Disabilities* 20(3): 263-280. DOI: 10.1177/1744629515614192

Sakdalan JA, Shaw J, and Collier V (2010) Staying in the here-and-now: A pilot study on the use of dialectical behaviour therapy group skills training for forensic clients with intellectual disability. *Journal of Intellectual Disability Research* 54(6), 568-572.

Singh NN, Lancioni GE, Karazsia BT, Winton ASW, Myers RE, Singh ANA, Singh ADA, and Singh J (2013) Mindfulness-Based Treatment of Aggression in Individuals with Mild Intellectual Disabilities: A Waiting List Control Study. *Mindfulness* 4:158-167. DOI: 10.1007/s12671-012-0180-8

Smiley E (2005) Epidemiology of mental health problems in adults with learning disability: an update. *Advances in Psychiatric Treatment* 11(3): 214-222. DOI: 10.1192/apt.11.3.214

Smith JA, Flowers P, and Larkin M (2012) *Interpretative Phenomenological Analysis: Theory, Method and Research.* London, UK: SAGE Publications.

Smith JA, and Osborn M (2015) Interpretative Phenomenological Analysis. In: Smith JA (ed.) *Qualitative Psychology. A practical guide to research methods.* London: SAGE Publications, pp. 26-53.

Stoffers JM, Vollm BA, Rucker G, Timmer A, Huband N, and Lieb K (2012) Psychological therapies for people with borderline personality disorder. *The Cochrane database of systematic reviews* 15(8): CD005652

Sturmey P (2006) On some recent claims for the efficacy of cognitive therapy for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 19: 109-118.

Sutton J, and Austin Z (2015) Qualitative Research: Data Collection, Analysis, and Management. *The Canadian Journal of Hospital Pharmacy* 68(3): 226-231. DOI: 10.4212/cjhp.v68i3.1456

Tajfel H, and Turner JC (2004). The Social Identity Theory of Intergroup Behavior. In: Jost JT and Sidanius J (eds.) *Key readings in social psychology. Political psychology: Key readings.* New York, NY, US: Psychology Press, pp. 276-293.

Thomson M, and Johnson P (2017) Experiences of women with learning disabilities undergoing dialectical behaviour therapy in a secure service. *British Journal of Learning Disabilities* 45(2): 106-113. DOI: 10.1111/bld.12180

Venville A, Sawyer AM, Long M, Edwards N, and Hair S (2015) Supporting People With an Intellectual Disability and Mental Health Problems: A Scoping Review of What They Say

About Service Provision. *Journal of Mental Health Research in Intellectual Disabilities* 8(3): 186-212. DOI: 10.1080/19315864.2015.1069912

Wink LK, Erickson CA, Chambers JE, and McDougle CJ (2010) Co-Morbid Intellectual Disability and Borderline Personality Disorder: A Case Series. *Psychiatry* 73(3): 277-287. DOI: 10.1521/psyc.2010.73.3.277

Yalom ID (2008) *The theory and Practice of Group Psychotherapy Fifth Edition.* Hachette, UK: Basic Books.

Yildiran H, and Holt RR (2014) Thematic analysis of the effectiveness of an inpatient mindfulness group for adults with intellectual disabilities. *British Journal of Learning Disabilities* 43(1): 49-54. DOI: 10.1111/bld.12085

Zolkowska T, and Kaliszewska K (2014) The social construction of social identity of people with intellectual disability. *International Journal of Developmental Disabilities* 60(1): 3-12. DOI: 10.1179/2047387712Y.0000000009

Chapter 3

Contributions to theory and clinical practice.

Contributions to Theory and Clinical Practice

This research focused on exploring the value of 'third-wave' psychological therapies in intellectual disability (ID) services. The literature review explored the efficacy of mindfulness-based interventions (MBIs) for caregivers of individuals with ID, whilst the empirical paper explored service user experiences of adapted Dialectical Behaviour Therapy (DBT). This final chapter integrates the findings from both papers in relation to the following: 1) implications for future research and theory development, 2) clinical implications, 3) personal reflections.

Implications for future research and theory development

Findings from the literature review and empirical investigation offer valuable contributions to the evidence-base for 'third-wave' therapies within ID services. However, both papers highlight the paucity of research pertaining to the use of such psychological therapies within ID services, and within the field of ID more generally; thus, indicating several recommendations for future research.

Understanding burnout/resilience among caregivers of individuals with ID

Whilst research clearly documents the existence of stress and burnout among caregivers of individuals with ID and the truly detrimental effects this exerts for both caregivers and care recipients (Hwang & Kearney, 2014), there are no comprehensive theoretical frameworks to explain such phenomena (Devereux, Hastings & Noone, 2009). The development of such theoretical frameworks is vital in order to highlight important clinical implications and protect the wellbeing of carers and care recipients alike. Existing research highlights potential risk and protective factors, however it is not clear which variables, such as personal characteristics (e.g. coping style, psychological flexibility), organisational characteristics (e.g. work demands, appropriate training, role ambiguity) or care recipient characteristics (e.g. challenging behaviour, severity of impairment) are most influential in the development and maintenance of

stress and burnout and subsequent psychological distress (Flynn et al., 2018; Lindo et al., 2016; Rose et al., 2013; Smyth, Healy & Lydon, 2014). Further research is therefore warranted to explore this complex array of potential predictors, moderators and mediators, to understand how employees can be best prepared and supported by organisations, and how services can best support families of individuals with ID.

Given the homogeneity present among professional caregivers (e.g. support staff, nurses, social workers, psychologists) it would be useful for future research to explore potential predictors, moderators and mediators in relation to different professional backgrounds. For parental caregivers, it is crucial that research encompasses mothers *and* fathers; something which is lacking among the existing literature, with much research focused on mothers alone (Rivard et al., 2014). Additionally, parental research should encompass parents of individuals with a range of IDs as opposed to largely individuals with Autism Spectrum Disorder.

Furthermore, research has demonstrated significantly elevated levels of emotional and behavioural difficulties among siblings of children with IDD (Blakemore, Strazdins & Gibbings, 2009), however the evidence within this field remains limited. Future research may wish to further explore this avenue to further our understanding of the development and presentation of such difficulties, in order to ensure that siblings of individuals with IDD can be appropriately and effectively supported.

Theoretical issues around emotional dysregulation and interpersonal difficulties in ID

Emotional dysregulation and difficulties managing interpersonal relationships are core features of Borderline Personality Disorder (BPD), assumed to arise due to an interaction between biological vulnerabilities and invalidating, traumatic or abusive environments (Linehan, 1993). Whilst evidence clearly demonstrates that individuals with ID have an extremely elevated risk of experiencing environmental stress such as sexual abuse (Cambridge et al., 2006; Turk &

Brown, 1993), disrupted attachments (Hollins & Sinason, 2000) and invalidating environments (Wink et al., 2010) there is a significant lack of research exploring how such experiences may contribute to the development of emotional dysregulation and interpersonal difficulties among this population. Of the small amount of research that does exist, focus has tended to be on the identification of BPD in individuals with ID, including the validity of diagnostic tools (e.g. Alexander & Cooray, 2003; Alexander et al., 2012) and has been fraught with contention. However, important theoretical issues extend beyond the identification of such difficulties, such as the development, presentation and maintenance of such difficulties among individuals with ID. Questions remain as to whether individuals with ID are more prone to developing difficulties regulating emotions and interpersonal relationships; whether such difficulties present similarly to individuals without ID; and whether such difficulties would be consistent with a BPD diagnosis.

Further research is therefore warranted that facilitates a more comprehensive understanding of the development and maintenance of emotional dysregulation and interpersonal difficulties among individuals with ID, which acknowledges their cultural framework (e.g. history of institutionalisation, trauma/abuse). Such research may highlight the importance of a formulation-based approach, and offer significant implications for differential diagnosis, intervention and the ways in which systems support individuals with ID throughout their lives (Wink et al., 2010). Encouraging a formulation-based approach may also be invaluable in reducing stigma and blame (often associated with BPD; Aviram, Brodsky & Stanley, 2006), which are already all-too-familiar experiences for individuals with ID that exert detrimental effects on psychological wellbeing (Jahoda & Markova, 2004).

Social identity and psychological distress among individuals with ID

Although not extracted as an overarching theme in the empirical paper, many individuals described *"people like me"* and inferred that having an ID meant they were part of an inherently flawed population. Research from social identity theory (Tajfel & Turner, 2004) and social rank theory (Price & Soloman, 1987; Gilbert, 1992; 1997) highlight the detrimental effects that perceived inferiority can have on the development of shame, poor self-esteem and subsequent psychological distress. Whilst there is minimal research specifically exploring the impact of social experiences and core cognitive processes on psychological distress among individuals with ID, one study has identified social processes as fundamental in the development of negative self-beliefs for individuals with ID (Dagan & Waring, 2004). The paper indicates that heightened exposure to stigma among individuals with ID may increase their sensitivity to social processes, and leave them vulnerable to developing sociotropic schema (identified as a risk factor for depression among non-ID populations; Beck et al., 1983). Thus, offering valuable insights into the theoretical understandings of the elevated levels of mental health difficulties among individuals with ID. Further research may wish to further explore these theoretical links between the social experiences of individuals with ID, core cognitive processes and psychological distress in order to inform appropriate support and interventions for this population.

The effects of specific DBT components

Findings from the empirical study indicated that participants struggled to fully comprehend some of the more abstract DBT concepts. It may be interesting to further explore people with ID's understanding of specific components, such as the three 'minds' (emotional mind, reasonable mind and wise mind) and mindfulness, and whether limited understanding of such concepts impacts on outcome.

There is an emerging evidence-base for the use of DBT skills as a stand-alone intervention (Linehan, 2015; Safer & Jo, 2010; Soler et al., 2009). However, findings from the empirical study indicate that participants relied heavily on their individual therapy sessions to consolidate and generalise learning, suggesting that if delivered in isolation, DBT skills would significantly reduce therapeutic gains for individuals with ID. It would be interesting for future research to explore this avenue further by utilising component analyses to understand the effects of each component of DBT (e.g. skills group/individual sessions/between-session coaching) for individuals with ID.

Furthermore, the findings from the empirical study indicated that participants may have benefitted from more behaviourally-based skills which could be learned through experiential teaching; indicating that individuals with ID may benefit from specific components of the skills modules than others. Future research may also wish to utilise component analyses in order to explore the relative contribution of the different DBT skills (e.g. acceptance vs. change skills/cognitive vs. behavioural skills).

Carer involvement in therapeutic processes

The empirical paper posed interesting questions for the involvement of carers within the therapeutic process. Future research may wish to formally investigate the impact that carer involvement exerts on: service user participation within the group process; consolidation and generalisation of skills; and therapeutic outcomes. It would be valuable to consider this from the perspectives of service users, carers and DBT facilitators, as well as through formal measurements.

Enhancing accessibility of DBT for individuals with ID

Whilst recommendations have been made regarding how to adapt material and deliver information for individuals with ID in order to enhance accessibility (e.g. Gore & Hastings,

2016; Lindsay et al., 2013) further exploration of what service users consider helpful would be invaluable. Focus groups may be a valuable method of evaluating specific therapeutic adaptations, which embraces the spirit of co-production. Research may also wish to formally explore the efficacy of different methods of adapting DBT on therapeutic outcomes. It is however, important that any adaptations do not mean that material is too divergent from standard material such that it impacts on overall fidelity to the model. Future research should consider working towards a standardised model of adapted DBT for individuals with ID with this in mind.

Clinical implications

Perhaps the most significant clinical implication to emerge from the current research is the finding that offering 'third-wave' psychological therapies within ID services can have valuable therapeutic outcomes. Specifically, caregivers (particularly parents) can benefit from MBIs and experience reduced levels of stress, and service users can benefit from DBT in the intended way, when presented in an accessible format.

Staff support systems within ID services

Given the detrimental consequences caregiver stress exerts for caregivers, care recipients and the organisation, it is crucial that employers offer adequate support systems for professionals within their workplace. In line with NICE (2009) guidance, organisations should provide employees with adequate access to support systems to meet the demands of their role and promote positive wellbeing. Organisations should consider embedding appropriate support within ID services such as debriefing sessions (Eppich & Cheng, 2016; Gunasingam et al., 2015), reflective practice groups (Redmond, 2017), and self-care (Weight et al., 2013) and stress management training (Rowe, 2006) which have all been highlighted as effective in healthcare settings. Additional structural and organisational strategies such as modifying

clinical work processes, flexible working and shortened shifts may also be necessary to reduce workplace stress and burnout (Linzer et al., 2015; Parshuram et al., 2015; West et al., 2016).

Use of MBIs for staff in ID services

The findings from the literature review indicate that MBIs are more effective in reducing stress for caregivers when they are longer in length and/or intensity. Organisations should therefore consider avoiding the delivery of MBIs through one-off workshops, and focus on offering workshops delivered over a longer period. It is likely that regardless of how the initial training is delivered, ongoing support and practice will be required in order for the MBI to be effective in the longer-term. Services may therefore wish to provide initial training followed by regular practice sessions. This could take the form of formal, longer practices on a fortnightly or monthly basis, as well as embedding mindfulness practices into daily practice (e.g. during team meetings/handovers) which has been demonstrated as effective within other healthcare settings (Braganza et al., 2018). Staff could be encouraged to take turns in facilitating regular in-house practice sessions.

Supporting families of individuals with ID

Findings from the literature review indicate that providing MBIs to parental carers is an effective way of reducing caregiver stress and protecting caregiver and service user wellbeing alike. Thus, MBIs for carers could be offered within a developmental systems approach in ID services (Crnic et al., 2017). Given their potentially multi-faceted influence on service user and familial well-being, MBIs may be particularly effective and cost-efficient interventions for ID services. As with professional caregivers, ongoing support and practice will likely be required in order for effects to be maintained; for parents this may be in the form of booster sessions, daily practices or consultations with clinicians.

Clinicians should also remain mindful of the need to provide adequate support for the caregivers/families of individuals with ID. Clinicians should conduct thorough assessments (e.g. of coping styles, optimism and social support) with families to identify the level and etiology of stress and offer appropriate support to promote parental resilience (Peer & Hillman, 2014). This may take the form of skills training, educational materials or completing referrals for counselling. Social support has been identified as a strong predictor of resilience among parents of individuals with ID (Sipal et al., 2010) and clinicians should not underestimate the importance of their role in providing this for families. Having a key worker who regularly links in with families may serve as key in its own right; additional referrals to available support groups may also be necessary, as well as exploring with carers ways of integrating their natural supports into their daily routines (Peer & Hillman, 2014).

Further adapting delivery and materials

Findings from the empirical paper highlighted that despite initial efforts, participants struggled to fully understand DBT concepts, indicating that further modification may be necessary for DBT to be meaningful and accessible for individuals with ID. Clinicians should draw upon suggested adaptations such as:

- Utilising **visual methods** such as *'Blob People'* (Wilson & Long, 2009); physical objects and drawings to make abstract concepts more concrete (Gore & Hastings, 2016); thought/speech bubbles to represent events and thinking processes (Willner, 2009); photographs to enhance understanding (Baum & Lynggaard, 2016); physical objects to represent closeness/distance, size and inter-relationships (Beard, Greenhill & Lloyd, 2016); timers to indicate passage of time (Lloyd, Macdonald & Wilson, 2016).

- Utilise simple, concise and clear language; avoid abstract language and use concrete phrases (Gore & Hastings, 2016); re-name skills modules; avoid mnemonics (Lippold, 2016); and utilise service users' own choice of words (Baum & Lynggaard, 2016).

- Reduce pace of delivery, schedule regular breaks (Brown & Hooper, 2009); break information into smaller chunks, regularly check back for understanding; and reduce length of skills group (Lippold, 2016).

- Utilise **experiential teaching methods** where possible such as role play (Willner, 2009; Whitehouse et al., 2006) to explore how different interpretations can lead to different outcomes and emotions; and practical exercises to enhance skill development (e.g. blowing bubbles to develop breathing skills; Robertson, 2011).

- Consider video recording the modelling of skills or audio-record specific concrete instructions that talk service users through skills to reduce cognitive demands.

- Some participants in the empirical study voiced worries about the ending of DBT; it may be beneficial to consider offering booster sessions following a service users' withdrawal from DBT to further facilitate generalisation and maintain therapeutic outcomes (Wellman et al., 2015).

Training and support for clinicians

Connel and Wellbourn's (1991) model of self-efficacy highlights the importance of 'feeling competent' in persisting with a given task/activity, and observations in clinical practice throughout this research demonstrated how perceived lack of competence is often a barrier to clinician's delivering adapted psychological therapies in practice. Thus, considering ways of enhancing clinician's competence in delivering highly specialised, adapted, psychological therapies is crucial. Providing ongoing training and support, access to continuing professional development events and the development of peer support groups would all promote the enhancement of skills and competence.

Additionally, given the difficulties in identifying and recognising BPD in individuals with ID at present, it would be useful for DBT clinicians and referring clinicians to have appropriate training on identifying emotional regulation and interpersonal difficulties among this population. Sufficient education and training should be delivered which utilises a formulation-based approach to understanding the development and presentation of such difficulties among individuals with ID, to ensure that appropriate referrals are made and accepted.

Emphasising formulation

Throughout the interviews in the empirical study, many participants expressed the belief that DBT was a therapy specifically for people with ID who have inherent problems. It may be that when attempting to simplify materials, clinicians run the risk of paying less attention to formulation and focus more on the intervention. However, formulation of difficulties is essential to normalise difficulties and reduce self-blame (Johnstone & Dallos, 2006), which is particularly important for individuals with ID who already face elevated levels of stigma and shame (Dagnan, 2008).

Carer involvement

Findings from the empirical study highlighted that whilst caregivers played a crucial role in facilitating consolidation and generalisation of skills, their presence at skills group was often felt to hinder independence and engagement within the group process. Thus, services need to carefully consider the involvement of carers/support in the therapeutic process. An optimal arrangement may be one in which service users and carers/support attend concurrent, but separate groups. Where resource is limited, it would be worth offering separate sessions for carers/support at least once per module to ensure they gain vital knowledge of DBT skills enabling them to be well placed to model skills and promote skill development. At very least,

it is vital that clinicians continually consult service users to ascertain their preferences and accommodate these accordingly.

Personal reflections

I once read that the journey is just as important as the destination; and whilst reflecting on this research journey, it has never felt truer. As I initially embarked upon this journey, I had not anticipated the road that lay ahead. It is only now, as I take a step back I begin to appreciate just how much I have learnt along the way, and how valuable this has been in further developing myself both personally and professionally.

Reflective practice is a fundamental aspect of Interpretative Phenomenological Analysis (IPA) and is an essential skill that aids personal and professional development. The following reflections arose from personal thoughts, feelings and experiences, captured within a reflective diary kept throughout the research process. This process of reflection enabled me to enhance my self-awareness and acknowledge my own thoughts and preconceptions. This was invaluable in supporting me to bracket my own beliefs throughout the analysis (Chan & Chien, 2013).

My early experiences of volunteering at a 'special school' throughout my own school years sparked my initial love for supporting individuals with ID; and the heart-breaking realisation of the unjust lives people with ID lived initiated my dedication to support this population. Clinical training further highlighted the sheer lack of consideration afforded to people with ID, with their services under-resourced and their presence within research essentially absent. I felt as though people with ID were the 'forgotten population'; always last, always an after-thought. This left me utterly confused, because I have been so genuinely inspired by every single individual with an ID I have ever come across; they are funny, they are kind, they are sad, they are happy; they are *human*. They have lives, just like you and I.

Lives that must be worth living, and are of no less importance than any other. These reflections drove me to want to make their voices heard and their deserved place in research highlighted. On my core ID placement, the need for research pertaining to the use of DBT within ID services became apparent, which informed the decision to conduct the empirical paper.

Being a novice to qualitative research, engaging in an unfamiliar and novel approach evoked overwhelming anxiety. Although I was inspired by the opportunity to further develop my research skills within a new method, I noticed how I felt daunted by the prospect. The realisation that there was not one objective truth to be discovered, but instead an expectation that I facilitate and develop a rich understanding of multiple experiences evoked a huge sense of self-doubt and uncertainty. I became acutely aware of the reassurance that quantitative frameworks usually offered me. Reminding myself of the overarching research aims, and rekindling my passion for supporting this population enabled me to manage and work through this uncertainty.

I noticed feeling extremely apprehensive prior to conducting each interview; preoccupied with the responsibility of capturing 'rich enough' insights. I was particularly concerned with how the communication difficulties of participants may impact on their ability to respond to open questioning and offer detailed insights into their experiences. I contemplated the ways in which I could encourage this without contaminating the data, and became aware of the need repress my existing tendency as a Trainee Clinical Psychologist to adopt an interpretative stance, as this may have imposed my perception opposed to their own. This was particularly important given the tendency for people with ID to often provide socially desirable responses (Jobson et al., 2013). I became skilled at utilising effective open-ended prompts which encouraged participants to expand on their own interpretations of their experience, as well as noting down my interpretations rather than voicing them verbally.

I was struck by how participants' stories evoked strong emotional responses in me. I was filled with great sadness when participants talked of abusive or traumatic incidents, and frequently then felt angry due to the immorality described. At these times it was often impossible not to adopt my familiar therapeutic role to express empathy, validation and my opinion that such events were totally unacceptable. I also noticed how my sadness and anger presented the urge to challenge participants self-blame and self-criticism. Whilst at times my researcher role felt appropriately overridden by the need for humanity, I was careful not to allow this to permeate throughout the interview and acknowledged the importance of the interview remaining focused on the research objectives.

Throughout the transcription phase I was surprised at how quickly I disconnected from each participant. During each interview I built up a rapport with each individual and felt immersed within the emotions which accompanied their story. However, transcription required me to pay much greater attention to each individual word, which seemed to cause me to connect much more with the content rather than the individual. I recognised that in supervision, when I recalled specific individuals and their interviews from memory, much of the energy and emotion captured within the interview became more salient than at times where I had been merely reading transcripts. I reflected on this and wondered whether the transcription process had left me less emotionally connected to each participants' story. It was then that I realised the importance of regularly referring back to my written reflections from the time of the interview.

An interesting, and unexpected observation throughout the entire process was the overwhelming responsibility I felt to truly represent each participants' individual experience. This became particularly evident during the analysis phase when I noticed how I became fixed on protecting the narrative of each participant. Whilst this helped me to ensure that emergent themes were truly representative of, and grounded within the data, it also proved to be

unhelpful. For example, I found it extremely difficult to "let go" of themes, as I felt compelled to somehow include absolutely everything; I felt guilty about selecting only certain themes and quotes. In hindsight, I also feel that this responsibility made me reluctant to make my own meaningful interpretations for fear of in some way losing the participants' true experience. Acknowledging this and taking a step back enabled me to realign with the fundamental 'double hermeneutic' process, and develop confidence in building up my own thoughts and interpretations.

I had not fully appreciated how laborious qualitative data analysis is, and the tortuously slow nature of the analysis presented a significant challenge to my usual tendency to work at a fast pace. Nevertheless, perseverance paid off, and, as a narrative began to develop I was pleased that I challenged myself to adopt a qualitative approach.

In the midst of conducting this research, I returned to commence a clinical placement within an adult community ID team, with a specific focus on delivering adapted DBT. However, it quickly became evident that there were difficulties in recruiting service users to DBT, and there were ongoing discussions regarding the future of DBT within the service. Clinicians oscillated between optimism and pessimism, and generally presented as being stuck as to what the future held for DBT within the service. I noticed feeling extremely disheartened by the prospect of the DBT group folding. I could not help but hear only the negative comments regarding the usefulness of DBT for people with ID, and I noticed how a research project I had initially felt passionate about felt like a complete waste of time. Taking a step back and reflecting on these discussions enabled me to realise how the project was anything but a waste of time, and was actually more warranted than ever. I had been so caught up in my deflated emotions I had been unable to see that the lack of research pertaining to adapted DBT for people with ID was exactly what was perpetuating the current uncertainty and pessimism. I am now thankful for being involved in these tough discussions, as it helped me to re-realise the

importance of this research for clinical practice and enabled me to recover and further enhance my motivation to undertake the project. Importantly, I accepted that the intention was not an attempt to "save" DBT, but rather an effort to highlight important clinical implications to help inform clinical decision making; and I hope that I have managed to do just that.

For me, the completion of this research symbolises the beginning of the end of my clinical training, and the outset of my transition to qualified life. As somebody who continually doubts their ability, I have been able to take pleasure from reflecting on this difficult journey, and have been filled with an overwhelming sense of accomplishment and pride. Over time, I have developed new found confidence in my ability, and have realised that I am capable of much more than I give myself credit for. I have no doubt that the all-too-familiar experiences of anxiety and self-doubt will accompany me as I take my next steps into qualified life, however I will endeavour to continue persevering with new challenges in the hope of fulfilling my ambition to continually grow both personally and professionally in my new role as a Clinical Psychologist.

References

Alexander, R. T., & Cooray, S. (2003). Diagnosis of personality disorder in learning disability. *British Journal of Psychiatry, 182*(S44), 28-33. doi: 10.1192/bjp.182.44.s28

Alexander, R. T., Chester, V., Gray, N. S., & Snowden, R. J. (2012). Patients with personality disorders and intellectual disability – closer to personality disorders or intellectual disability? A three-way comparison. *Journal of Forensic Psychiatry & Psychology, 23*(4), 435-451. doi: 10.1080/14789949.2012.694462

Aviram, R. B., Brodsky, B. S., & Stanley, B. (2006). Borderline Personality Disorder, Stigma, and Treatment Implications. *Harvard Review of Psychiatry, 14*(5), 249-256. doi: 10.1080/10673220600975121

Baum, S., & Lynggaard, H. (2016). Systemic psychotherapy. In: N. Beail. (Ed.). *Psychological therapies and people who have intellectual disabilities* (pp. 74-81). Leicester: British Psychological Society.

Beard, K., Greenhill, B., & Lloyd, J. (2016). Cognitive analytic therapy. In: N. Beail. (Ed.). *Psychological therapies and people who have intellectual disabilities* (pp. 35-43). Leicester: British Psychological Society.

Beck, A. T. (1987). Cognitive models of depression. *Journal of Cognitive Psychotherapy: An International Quarterly, 1,* 5-37.

Blakemore, T., Strazdins, L., & Gibbings, J. (2009). Measuring family socioeconomic position. *Australian Social Policy, 8*, 121-168.

Braganza, S., Young, J., Sweeny, A., & Brazil, V. (2018). OneED: Embedding a

    mindfulness-based wellness programme into an emergency department. *Emergency*

    Medicine Austalasia. Advanced online publication. doi: 10.1111/1742-6723.12977

Brown, F., & Hooper, S. (2009). Acceptance and commitment therapy (ACT) with a learning

    disabled young person experiencing anxious and obsessive thoughts. *Journal of*

    Intellectual Disabilities, 13, 195-200. doi: 10.1177/1744629509346173

Cambridge, P., Beadle-Brown, J., Milne, A., Mansell, J., & Whelton, B. (2006). *Exploring*

    the incidence, risk factors, nature and monitoring of adult protection alerts.

    Canterbury: Tizard Centre.

Chan, Z. C. Y., Fung, Y-L., & Chin, W-T. (2013). Bracketing in Phenomenology: Only

    Undertaken in the Data Collection and Analysis Process. *The Qualitative report,*

    18(30), 1-9.

Connell, J. P., & Wellbourn, J. G. (1991). Competence, autonomy and relatedness: a

    motivational analysis of self-esteem processes. In: M. Gunnar & L. A. Sroufe (Eds.).

    Minnesota Symposium on Child Psychology, Vol 22 (pp.43-77). Minneapolis, MN:

    UMP.

Crnic, K. A., Neece, C. L., McIntyre, L. L., Blacher, J., & Baker, B. L. (2017). Intellectual

    Disability and Developmental Risk: Promoting Intervention to Improve Child and

    Family Well-Being. *Child Development, 88*(2), 436-445. doi: 10.1111/cdev.12740

Dagnan, D. (2008). Psychological assessment with people with learning disabilities and

    mental health. *Advances in Mental Health and Learning Disabilities, 2*(4), 4-8. doi:

    10.1108/17530180200

Dagnan, D., & Waring, M. (2004). Linking Stigma to Psychological Distress: Testing a Social-Cognitive Model of the Experience of People with Intellectual Disabilities. *Clinical Psychology and Psychotherapy, 11,* 247-254. doi: 10.1002/cpp.413

Devereux, J., Hastings, R., & Noone, S. (2009). Staff Stress and Burnout in Intellectual Disability Services: Work Stress Theory and its Application. *Journal of Applied Research in Intellectual Disabilities, 22*(6), 561-573. doi: 10.1111/j.1468-3148.2009.00509.x

Eppich, W. & Cheng, A. (2016). Promoting excellence and reflective learning in simulation (PEARLS): Development and rationale for a blended approach to health care simulation debriefing. *Simulation in Healthcare, 10*(2), 106-115.

Flynn, S., Hastings, R., Gillespie, D., McNamara, R., & Randell, E. (2018). Is the amount of exposure to aggressive challenging behaviour related to staff work-related well-being in intellectual disability services? *Research in Developmental Disabilities.* Advance online publication. doi: 10.1016/j.ridd.2018.04.006

Gilbert, P. (1992). *Depression: The Evolution of Powerlessness.* Hove, UK: Lawrence Erlbaum Associates.

Gilbert, P. (1997). The evolution of social attractiveness and its role in shame, humiliation, guilt and therapy. *British Journal of medical Psychology, 70,* 113-147.

Gore, N. J., & Hastings, R. P. (2016). Mindfulness and acceptance-based therapies. In N. Beail (Ed.). *Psychological therapies and people who have intellectual disabilities* (pp. 44-54). Leicester: British Psychological Society.

Gunasingam, N., Burns, K., Edwards, J., Dinh, M., & Walton, M. (2015). Reducing stress and burnout in junior doctors: the impact of debriefing sessions. *Postgraduate Medical Journal, 91*(1074), 182-187. doi: 10.1136/postgradmedj-2014-132847

Hwang, Y-S., & Kearney, P. (2014). Mindful and Mutual Care for Individuals with Developmental Disabilities: A Systematic Literature Review. *Journal of Child and Family Studies, 23*(3), 497-509. doi: 10.1007/s10826-012-9707-9.

Jahoda, A., & Markova, I. (2004). Coping with social stigma: people with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research, 48*(8), 719-729. doi: 10.1002/cpp.413

Jobson. L., Stanbury, A., & Langdon, P.E. (2013). The self-and other-deception questionnaires-intellectual disabilities (SDQ-ID and ODQ-ID): Component analysis and reliability. *Research in Developmental Disabilities, 34*(10), 3576-3582. DOI: 10.1016/J.RIDD.2013.07.004

Johnstone, L., & Dallos, R. (2006). Introduction to formulation. In L. Johnstone & R. Dallos (Eds.). *Formulation in psychology and psychotherapy: Making sense of people's problems* (pp. 1-6). London: Routledge.

Lindo, E. J., Kliemann, K. R., Combes, B. H., & Frank, J. (2016). Managing Stress Levels of Parents of Children with Developmental Disabilities: A Meta-Analytic Review of Interventions. *Family Relations, 65*(1), 207-224. doi: 10.1111/fare.12185

Lindsay, W. R., Jahoda, A. J., Wilner, P., & Taylor, J. L. (2013). Adapting psychological therapies for people with intellectual disabilities I: Assessment and cognitive deficit considerations. In: J. L. Taylor, W. R. Lindsay & R. P. Hastings (Eds.). *Psychological therapies for adults with intellectual disabilities* (pp. 69-84). Chichester, UK: Wiley-Blackwell.

Linehan, M. M. (1993). *Cognitive-Behavioral Treatment of Borderline Personality Disorder.* New York: The Guilford Press.

Linehan, M. M. (2015). *DBT Skills Training Manual, Second Edition.* New York, NY: The Guilford Press.

Linzer, M., Poplau, S., Grossman, E. Varkey, A., Yale, S. Williams, E. … Barcouche, M. (2015). A Cluster Randomized Trial of Interventions to Improve Work Conditions and Clinician urnout in primary Care: Results from the Healthy Work Place (HWP) Study. *Journal of general internal medicine, 30*(8), 1105-1111. doi: 10.1007/s11606-015-3235-4

Lippold, T. (2016). Dialectical behaviour therapy. In: N. Beail (Ed.). *Psychological therapies and people who have intellectual disabilities* (pp. 55-60). Leicester: British Psychological Society.

National Institute for Health and Care Excellence. (2009). *Mental wellbeing at work.* London: Author.

Lloyd, H. F., Macdonald, A., & Wilson, L. (2016). Solution-focused brief therapy. In: N. Beail (Ed.). *Psychological therapies and people who have intellectual disabilities* (pp. 61-70). Leicester: British Psychological Society.

Parshuram, C. S., Amaral, A. C., Ferguson, N. D., Baker, G. R., Etchells, E. E., Flintoff, V., … Friedrich, J. O. (2015). Patient safety, resident well-being and continuity of care with different resident duty schedules in the intensive care unit: a randomized trial. *Canadian Medical Association Journal, 187*(5), 321-329. doi: 10.1503/cmaj.140752

Peer, J. W., & Hillman, S. B. (2014). Stress and Resilience for Parents of Children With Intellectual and Developmental Disabilities: A Review of key Factors and

Recommendations for Practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92-98. doi: 10.1111/jppi.12072

Price, J., & Soloman, L. (1987). Depression as yielding behaviour: an animal model based on Schjelderup-Ebb's pecking order. *Ethology and Sociobiology, 8*, 85-98.

Redmond, B. (2017). *Reflection in Action.* London: Routledge.

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Developmental Disorders, 44*(7), 1609-1620. doi: 10.1007/s10803-013-2028-z

Robertson, B. (2011). The adaptation and application of mindfulness-based psychotherapeutic practices for individuals with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities, 5*(5), 46-52.

Rose, J., Mills, S., Slva, D., & Thompson, L. (2013). Client characteristics, organisational variables and burnout in care staff: The mediating role of fear of assault. *Research in Developmental Disabilities, 34*(3), 940-947. doi: 10.1016/j.ridd.2012.11.014

Rowe, M. M. (2006). Four-year longitudinal study of behavioral changes in coping with stress. *American Journal of Health Behavior, 30*(6), 602-612.

Safer, D. L., & Jo, B. (2010). Outcome from a randomized controlled trial of group therapy for binge eating disorder: Comparing dialectical behavior therapy adapted for binge eating to an active comparison group therapy. *Behavior Therapy, 41*(1), 106-120.

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, A. N. A., Adkins, A. D. A., & Singh, J. (2009). Mindful staff can reduce the use of physical restraints when providing care to individuals with intellectual disabilities. *Journal or Applied Research in Intellectual Disabilities, 22*(2), 194-202. doi: 10.1111/j.1468-3148.2008.00488.x

Sipal, R. F., Schuengel, C., Voorman, J. M., Van Eck, M., & Becher, J. G. (2010). Course of behaviour problems of children with cerebral palsy: The role of parental stress and support. *Child Care, Health & Development, 36,* 74-84. doi: 10.1111/j.1365-2214.2009.01004.x

Smyth, E., Healy, O., & Lydon, A. (2014). An analysis of stress, burnout, and work commitment among disability support staff in the UK. *Research in Developmental Disabilities, 47*, 297-305.

Soler, J., Pascual, J. C., Tiana, T., Cebria, A., Barrachina, J., Campins, M. J., et al. (2009). Dialectical behaviour therapy skills training compared to standard group therapy in borderline personality disorder: A 3-month randomised controlled clinical trial. *Behaviour Research and Therapy, 47*(5), 353-358.

Tajfel, H., & Turner, J. C. (2004). The Social Identity Theory of Intergroup Behavior. In: J. T. Jost and J. Sidanius (Eds.). *Key readings in social psychology. Political psychology: key readings* (pp. 276-293). New York, NY: Psychology Press.

Turk, J., & Brown, H. (1993). The sexual abuse of adults with learning disabilities: Results of a two-year incidence survey. *Mental handicap research, 6,* 193-216.

Weight, C. J., Sellon, J. L., Lessard-Anderson, C. R., Shanafelt, T. D., Olsen, K. D., & Laskowski, E. R. (2013). Physical activity, quality of life, and burnout among physician trainees: the effect of a team-based, incentivized exercise program. *Mayo Clinic Proceedings, 88*(12), 1435-1442. doi: 10.1016/j.mayocp.2013.09.010

Wellman, J., Barter, B., & Steele, A. (2015). Group top-up therapy for service users: Joshua Wellman and colleagues argue that those with learning disabilities could benefit from having a mix of individual and group therapy. *Learning Disability Practice, 18*(8), 33-38.

West, C. P., Dyrbye, L. N., Erwin, P. J., & Shanafelt, T. D. (2016). Interventions to prevent and reduce physician burnout: a systematic review and meta-analysis. *Lancet, 388*(10057), 2272-2281. doi: 10.1016/S0140-6736(16)31279-X

Whitehouse, R. M., Tudway, J. A., Look, R. & Kroese, B. S. (2006). Adapting individual psychotherapy for adults with intellectual disabilities: a comparative review of the cognitive-behavioural and psychodynamic literature. *Journal of Applied Research in Intellectual Disabilities, 19,* 55-65.

Wilner, P. (2009). A cognitive behavioural formulation of anger in a man with intellectual disability. In P. Sturmey (Ed.). *Clinical case formulation: Varieties of approaches* (pp. 267-281). New York: Wiley.

Wilson, P., & Long, I. (2009). *The Big Book of Blobs.* Bicester: Speechmark.

Wink, L. K., Erickson, C. A., Chambers, J. E., & McDougle, C. J. (2010). Co-Morbid Intellectual Disability and Borderline Personality Disorder: A Case Series. *Psychiatry, 73*(3), 277-287. doi: 10.1521/psyc.2010.73.3.277

Appendices

Ethical approval granted for 2017-16078 Service user experiences of Dialectical Behaviour Therapy (DBT) in a community learning disability service

E

ethics@bangor.ac.uk

Reply all|

Mon 04/09/2017, 16:23
Emma Louise Woolfall
Inbox

Dear Emma,

2017-16078 Service user experiences of Dialectical Behaviour Therapy (DBT) in a community learning disability service

Your research proposal number 2017-16078
has been reviewed by the Psychology Ethics and Research Committee
and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Appendix 2: Confirmation of Bangor University Liability Insurance

Hasilwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
Fax: 020 7847 8689

UMAL

TO WHOM IT MAY CONCERN

15th July 2017

Dear Sir/Madam

BANGOR UNIVERSITY
AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:-

PROFESSIONAL INDEMNITY

Certificate of Entry No.   UM026/95

Period of Cover   1 August 2017 to 31 July 2018

Limit of Indemnity   £5,000,000 any one claim and in the aggregate except for Pollution where cover is limited to £1,000,000 in the aggregate.

Cover provided by   U.M. Association Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Susan Wilkinson

For U.M. Association Limited

Appendix 3: IRAS Form – Ethics proposal

Reference: IRAS Version 5.5.2
                                                 17/WA/0321

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Service user experiences of DBT in adult community LD teams -V1

1. Is your project research?

◉ Yes ○ No

2. Select one category from the list below:

○ 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

○ Basic science study involving procedures with human participants

○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

◉ Study involving qualitative methods only

○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

○ Study limited to working with data (specific project only)

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?   ○ Yes   ◉ No

b) Will you be taking new human tissue samples (or other human biological samples)?   ○ Yes   ◉ No

c) Will you be using existing human tissue samples (or other human biological samples)?   ○ Yes   ◉ No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

☐ England
☐ Scotland

☑ Wales

☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

○ England

○ Scotland

◉ Wales

○ Northern Ireland

○ This study does not involve the NHS

---

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

☑ IRAS Form

☐ Confidentiality Advisory Group (CAG)

☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

○ Yes   ◉ No

---

5. Will any research sites in this study be NHS organisations?

◉ Yes   ○ No

---

6. Do you plan to include any participants who are children?

○ Yes   ◉ No

---

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes   ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

---

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or

who are offenders supervised by the probation service in England or Wales?

○ Yes   ◉ No

---

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes   ○ No

Please describe briefly the involvement of the student(s):
The chief investigator is a Trainee Clinical Psychologist studying on the Doctorate of Clinical Psychology at Bangor University in North Wales. The project will form the thesis for the Doctorate.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes   ○ No

---

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes   ◉ No

---

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes   ◉ No

Integrated Research Application System
Application Form for Research involving qualitative methods only

---

IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Service user experiences of DBT in adult community LD teams -V1

Please complete these details after you have booked the REC application for review.

REC Name:
Wales Rec 5

REC Reference Number:
17/WA/0321

Submission date:
22/09/2017

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Service user experiences of Dialectical Behaviour Therapy within adult community learning disability teams: A qualitative exploration.

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Miss	Emma Louise	Woolfall
Address	North Wales Clinical Psychology Programme		
	School of Psychology, Bangor University,		
	43 College Road, Bangor, Gwynedd		
Post Code	LL57 2DG		
E-mail	psp6c2@bangor.ac.uk		
Telephone	07748130772		
Fax	07748130772		

Give details of the educational course or degree for which this research is being undertaken:
Name and level of course/ degree:

Doctorate in Clinical Psychology (DClinPsy)

Name of educational establishment:
Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title Forename/Initials Surname
	Dr Gemma Griffith
Address	Centre for Mindfulness Research and Practice
	Bangor University,
	Bangor, Gwynedd,
Post Code	LL57 2DG
E-mail	g.m.griffith@bangor.ac.uk
Telephone	
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Emma Louise Woolfall	☑ Dr Gemma Griffith

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

◉ Student

◯ Academic supervisor

◯ Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Miss Emma Louise Woolfall
Post	Trainee Clinical Psychologist
Qualifications	BSc (Hons) in Psychology (1st class).
ORCID ID	
Employer	Betsi Cadwaladr University Health Board
Work Address	North Wales Clinical Psychology Programme
	School of Psychology, Bangor
	Gwynedd
Post Code	LL57 2DG
Work E-mail	psp6c2@bangor.ac.uk
* Personal E-mail	louisewoolfall@gmail.com

Work Telephone
* Personal Telephone/Mobile 07748130772
Fax

This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.
A copy of a <u>current CV</u> (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Hefin Francis
Address	Bangor University, School of Psychology
	Brigantia Building, Penrallt Road
	Gwynedd
Post Code	LL57 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	01248388339
Fax	

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	NA
Sponsor's/protocol number:	NA
Protocol Version:	NA
Protocol Date:	
Funder's reference number:	
Project website:	

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

◯ Yes   ⦿ No

Please give brief details and reference numbers.

---

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

Adults with learning disabilities are at an increased risk of experiencing mental health difficulties and emotional distress (APA, 2013). As such, individuals with a learning disability, like anybody else, should be able to access a full range of psychological therapies (BPS, 2016). Whilst historically, individuals with a learning disability have been excluded from psychological therapies, governmental strategies now emphasise the need for services to be adapted to meet the needs of individuals with a learning disability.

Research has begun to focus on the efficacy of adapted psychological interventions for individuals with learning disabilities, and Dialectical Behaviour Therapy (DBT) is one such approach. DBT aims to help individuals develop skills to regulate emotions, tolerate distress and manage relationships, subsequently reducing unhelpful behaviours (Linehan, 1993). There are important reasons for ensuring that DBT is adapted so that it can be accessed by individuals with a learning disability, such as the fact that such individuals are particularly likely to have experienced invalidating environments and subsequent psychological and emotional difficulties.

The development of adapted DBT services for individuals with a learning disability is now being considered internationally and across a number of settings (McNair et al., 2016) and studies have reported promising outcomes such as reductions in aggression and risk-taking behaviour (e.g. Brown et al., 2014; Hall et al., 2013; Lew et al., 2006). Whilst this is promising, there remains a paucity of research within this field and there is insufficient evidence to draw firm conclusions regarding the efficacy of DBT among this population. There is a necessity for an enhanced understanding of its accessibility and suitability for individuals with a learning disability. This study therefore aims to further our understanding of service user experiences of adapted DBT in community adult learning disability services, in order to augment interventions and enhance treatment outcomes.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Participants will be approached who have recently received, or are currently receiving full programme DBT. This means that they are likely to be currently experiencing current emotional or relational difficulties which may be distressing for them. Additionally, the experience of DBT may be a difficult for some individuals. For this reason potential participants will be initially approached by their lead clinician, whom they are familiar with. Potential participants will be informed about the research project and asked if they would be interested in discussing the project further with the researcher. Potential participants will be made aware that discussion with the researcher will not mean that they are obliged to take part and reassured that their decision to take part or not, will not affect their current or future care. Participants will also be informed of their right to withdraw at any time without explanation.

The interview may feel demanding for some individuals and so regular breaks will be scheduled appropriately throughout the interview where required. Should a participant become distressed, the researcher will address immediate distress and seek further support for the individual should this be required. Participants will be made aware of whom they should contact should they feel particularly distressed (typically their lead clinician). Additionally, the researcher will inform the participants' lead clinician if they become particularly distressed. Participation will be drawn to a close should participants experience significant distress and feel unable or unwilling to continue.

The researcher will ensure that each individual has the capacity to consent to engage in the research. This would include presenting the consent form in a modality that allows the participant to make an informed decision. If there is any doubt regarding capacity to consent, the participant will be withdrawn from the sample.

Betsi Cadwaladr University Health Board (BCUHB) confidentiality procedures will be upheld throughout the research process and will be explained clearly to all participants prior to the qualitative interview. The primary researcher will also comply with the BCUHB lone worker policy whenever necessary during the data collection/conducting interviews.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

123

☐ Case series/ case note review

☐ Case control

☐ Cohort observation

☐ Controlled trial without randomisation

☐ Cross-sectional study

☐ Database analysis

☐ Epidemiology

☐ Feasibility/ pilot study

☐ Laboratory study

☐ Metanalysis

☑ Qualitative research

☐ Questionnaire, interview or observation study

☐ Randomised controlled trial

☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

What are the experiences of service users who have attended DBT in a community learning disability team?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

What components of DBT do service users believe are helpful/unhelpful?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Compared with the general population, adults with learning disabilities are at an increased risk of experiencing mental health difficulties and emotional distress (APA, 2013; Cooper & Bailer, 2001). The likelihood of experiencing a mental health difficulty is estimated to be 2 to 4 times greater for individuals with a learning disability (APA, 2013), with prevalence rates estimated to be between 30%-50% (Cooper et al., 2007; Smiley, 2005).

Throughout their lifetime individuals with learning disabilities are at significantly increased risk of facing discrimination, social exclusion, internal and external stigma and unrelenting adversity alongside inadequate social and emotional support. Additionally, adults with learning disabilities are significantly less likely to live independently away from their family home, be in employment, have long-term romantic relationships, have a well-established support network or be integrated into their community (Carr et al., 2016; Idusohan-Moizer, Sawicka, Dendle & Albany, 2015). Such life experiences likely predispose individuals with learning disabilities to mental health difficulties and emotional/psychological distress; as early experiences of trauma and invalidating environments may contribute to the development of difficulties regulating emotions, tolerating distress and managing interpersonal relationships (Wink et al., 2010). Thus, there is a necessity to develop and provide effective interventions in order to alleviate emotional distress and improve psychological functioning among this population.

Additionally, individuals with learning disabilities often display "challenging behaviours" such as aggression and self-injury (e.g. scratching, picking, cutting, burning, hitting oneself with or against an object) which can cause significant harm to self and others (Brown, Brown & Dibiasio, 2013; NICE, 2015). Whilst such behaviours often result from the interaction between personal and environmental factors, the numerous challenges faced by individuals with learning disabilities such as; communication difficulties, sensory impairments, sensory processing difficulties and physical or mental health problems may increase the likelihood of such behaviours developing (NICE, 2015). Brown et al. (2013) argues that emotional dysregulation is often a key contributing factor to challenging behaviour, and as such interventions should be provided that focus on building self-regulation skills in order to reduce the risk of harm and emotional distress among individuals with learning disabilities.

Historically, addressing the psychological needs of individuals with a learning disability has been perceived as difficult

(Butz, Bowling & Bliss, 2000) and despite the lack of empirical evidence highlighting that individuals with learning disabilities do not benefit from psychological interventions, "people with learning disabilities have generally been overlooked or actively excluded from psychotherapies" (Banks, 2006 p. 363). Fortunately, despite such concerns, there has been a small group of professionals and researchers who have believed in the value of engaging individuals with learning disabilities in psychotherapeutic interventions (Banks, 2006). Additionally, an increasing number of recent government strategies and legislation are emphasising the need for services to be adapted in order to meet the needs of individuals with learning disabilities, who like anybody else, should have access to a full range of psychological therapies (Department of Health, 2010; BPS, 2016). Whilst some mainstream psychology services may be beneficial for individuals with a learning disability, some will require an adaptation to the method due to the possibility of cognitive deficits impacting on the therapeutic process (Beail 2013; Lindsay et al. 2013).

Recently research has begun to focus on and explore the effectiveness of adapted psychological interventions for individuals with learning disabilities. Cognitive Behavioural Therapy (CBT) is a well-established intervention, and is the psychological treatment of choice among the general population for a range of clinically significant problems such as depression, anxiety and anger (Hofmann, Asnaani, Vonk, Sawyer & Fang, 2012; Cuijpers et al., 2013). Recent research has also highlighted its effectiveness in reducing a range of emotional and inter-personal difficulties such as anger, depression, anxiety and psychotic symptoms (Nicoll et al., 2013; McGillivray et al., 2008; Wright, 2013; Haddock et al., 2014) particularly if reasonable adaptations/adjustments are made to make therapy accessible (Prout & Browning, 2011). Despite this, it is important to acknowledge that CBT may not be suitable for all individuals or for all psychological difficulties.

Mindfulness based stress reduction (Kabat-Zinn, 1990), Mindfulness based cognitive therapy (MBCT; Segal, Williams, & Teasdale, 2002), Dialectical Behaviour Therapy (DBT; Linehan, 1993) and Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999) are all part of the 'third wave' of cognitive behavioural models; such models are relatively new forms of psychological interventions and are becoming increasingly popular interventions among the general population. There is a growing body of research demonstrating that symptoms of anxiety and depression can be significantly reduced by MBCT (Hoffman et al., 2010; Vollestad et al., 2012) and ACT (Sharp, 2012; Levin, Hildebrandt, Lillis & Hayes, 2012). Whereas DBT has been shown to effectively stabilise and control self-destructive behaviour and improve compliance (Panos, Jackson, Hasan & Panos, 2013). A Cochrane review found that DBT improved outcomes for self-harm compared to standard care (Hawton et al., 1999) as well as for anger, parasuidality and mental health in individuals with borderline personality disorder (Binks et al., 2006). Over the past decade there has been emerging evidence for the use of mindfulness (Hwang & Kearney, 2013; Singh et al., 2011) and DBT (Lew et al., 2006; Sakdalm et al., 2010) among individuals with learning disabilities.

Dialectical Behaviour Therapy (DBT) was originally developed by Marsha Linehan (1993) as an approach for working with individuals with a diagnosis of borderline personality disorder (BPD). The approach assumes that individuals with BPD lack skills in managing distress, interacting with others and regulating emotions, as well as that there are a number of personal and environmental factors which prevent individuals from acting the most effective way and/or reinforce maladaptive behaviours. DBT aims to help individuals learn new skills and decrease unhelpful behaviours. DBT is underpinned by a dialectical philosophy which relates to the tension of holding on to opposing ideas simultaneously; a key dialectic is balancing 'acceptance' and 'change'. DBT is described as a third-wave CBT approach because it incorporates many principles and techniques of CBT (e.g. cognitive restructuring, exposure) whilst also drawing on Eastern philosophy in promoting mindful awareness. DBT has since been modified and developed for co-morbid difficulties such as eating disorders, across the lifespan, including with suicidal adolescents and in a range of clinical settings (Feigenbaum, 2008).

DBT is one such psychological therapy which individuals with learning disabilities should also have full access to. Whilst this is true, in practice DBT can be intellectually demanding (due to unfamiliar terminology, use of mnemonics for key concepts and diary cards) and so for DBT to be accessible for individuals with a learning disability, some adaptations will be necessary. The structure of the therapeutic intervention can remain the same, but the language used both in verbal and written communication and the format of the skills training will need to be modified to accommodate the needs of individuals with a learning disability. Nevertheless, there are important reasons for ensuring that DBT can be accessed by individuals with learning disabilities, such as the fact that individuals with a learning disability are particularly likely to have experienced invalidating environments (described in the DBT approach) (Lew et al., 2006) and subsequent psychological and emotional difficulties including managing distress, regulating emotions and getting on with others. Individuals with learning disabilities are also at an increased risk of developing self-injurious, aggressive or destructive behaviours (Brown, Brown & Dibiasio, 2013).

The development of adapted DBT services for individuals with learning disabilities is now beginning to be considered internationally and across a range of settings (McNair, Woodrow & Hare, 2016) and a number of studies have reported promising outcomes including reductions in aggression and risk-taking behaviour (e.g. Brown et al., 2014; Charlton & Dykstra 2011; Hall et al., 2013; Lew et al., 2006). Whilst this is a promising development, there is still a paucity of research within this field and there is insufficient good quality evidence to draw firm conclusions regarding the efficacy of DBT among this population. Given the potential for DBT to be an extremely effective and beneficial intervention among this population, there is a necessity for an enhanced understanding of its accessibility and suitability for individuals with a learning disability. Literature regarding psychological research emphasises the importance of

understanding the ways in which individuals perceive psychological interventions and the impact this can have on outcome (Gordon, 2000); this can enhance the understanding of the processes that an individual experiences and responses to the intervention (Elliot, 2008). Whilst there are published studies exploring researchers' views of how service users adapted to DBT (Nee & Farman, 2007) and therapist's experiences of delivering DBT (McMain, Korman, & Dimeff, 2001) there is a lack of published literature exploring the experiences of DBT from the perspectives of service users'. Four studies to date have employed qualitative methodology in order to explore the experiences of individuals with a learning disability who have received DBT (Hall et al., 2013; Johnson & Thomson, 2016; Roscoe, Petalas, Hastings & Thomas, 2015; Thomson & Johnson, 2017). However, three of these have focused on DBT programs within inpatient forensic settings, which are likely to be inherently different from community based programs. Therefore, this study aims to further our understanding of service user experiences of adapted DBT programs in adult learning disability services, in order to inform and augment interventions to enhance treatment outcomes.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Participants:
Participants will be recruited from Adult Community Learning Disability Teams across North Wales. Individuals who have been in/are currently in full programme DBT will be eligible for inclusion (received/receiving individual sessions and skills group). It is hoped that 8 participants will be recruited in total.

Inclusion criteria
•Participants must have been assessed as having a learning disability and as such
will be currently open to a CLDT within North Wales.
•Participants must be over 18 years of age.
•Participants must be able to provide informed consent.
•Participants must have either have recently finished, or be currently attending
full programme DBT (individual sessions plus skills group).
•Participants currently attending DBT must have completed a minimum of 2 months
full programme DBT.
•Participants who have completed DBT will be eligible to take part if they have
finished within the last 12 months.

Exclusion criteria
•Individuals who are unable to provide informed consent.

Recruitment:
Clinicians within the community learning disability teams across North Wales will be made aware of the research project and the eligibility criteria, and will identify potential participants from their caseload. Clinicians will then provide information about the research project (both verbally and written) to potential participants. Clinicians will ascertain if the individual is willing to speak to the researcher about the project. The clinician will make it clear to the individuals that speaking to the researcher will not mean that they have to participate. If individuals are happy to discuss the research further, they will return an "I'm interested" (see appendix) form to the research team, which will include their contact details and state that they are happy for the researcher to contact them. The researcher will then contact the individual and arrange to meet to further discuss the research and participation.

If and individual agrees to take part in the research, the researcher will assess capacity to consent using a protocol based on the procedure followed by Arscott, Dagnan & Kroese (1998)(see appendix). Should the individual be considered as having the capacity to consent, they will be required to give their informed consent. Participants will be reassured that their decision to participate or not, will not affect their current or future care and they will be informed that they can withdraw from the study at any stage without explanation. Written consent will be obtained where possible. If the participant is unable to provide written consent then verbal consent will be given and recorded by the researcher.

After an individual has provided consent, the researcher will arrange a mutually convenient time for the interview to take place.

Design and Procedure:
There is increased recognition that qualitative perspectives contribute to service development and influence service provision (Sofaer, 1999; Dy et al., 2005). This project will use a qualitative approach to explore an area that has not been widely researched. The proposed methodology is interpretative phenomenological analysis (IPA; Smith, 1996), which is an approach that aims to try and understand the participants' lived experiences and how participants themselves make sense of their experiences.

Data collection will be in the form of semi-structured interviews, using open ended questions. Interviews will be audio recorded and transcribed verbatim, removing any patient identifiers. Transcripts will then be analysed for emerging themes and commonalities using IPA methodology. This will be discussed with the research supervisors.

Ethical approval from the relevant departments will be acquired before the recruitment of any participants.

Once participants have been identified and have agreed to discuss the research further, they will be contacted by the researcher and a time will be arranged to meet with the researcher to discuss in detail what taking part will entail. At this point participants will be provided with an appropriate full participation information sheet (in an accessible format) and will be given the opportunity to ask any questions that they might have in if required relation to the project. all participants will provide informed consent to take part.

When participants have consented to take part in the research, a time and date will be agreed for the semi-structured interview to take place. Interviews will take place in a quiet space within a convenient CLDT/NHS building or within the participants' own home if that is preferred. Interviews are anticipated to last 30 minutes to one hour. A semi-structured interview schedule will be used to explore service-users perspectives/experiences of DBT (see appendix). The interview schedule will be developed in conjunction with research supervisors and DBT clinicians. Interview questions will aim to give little guidance to allow the participants to discuss feely what is of importance to them regarding the context. A pilot interview will be conducted with Dr Carmel Harrison (supervisors) to ensure that questions eliciting perceptions and beliefs are open and non-directive.

Data management:
Data will be kept in accordance with bangor University and BCUHB procedures. Recorded interviews will be stored on a digital recorder which will be stored in a locked cabinet within Community learning Disability Team premises. Interviews will be downloaded onto an NHS/Social services computer and transcribed, with all identifying information removed. Original recorded interviews will then be destroyed following the transcription process.
Each participant will be assigned a research identification number so that all data will be anonymised and no identifiers will be stored on a computer. Transcripts will be stored in password-protected files with identifiers removed. Transcripts will be stored on a password protected computer or encrypted pen drive provided by NWCPP. Demographic information and consent forms will be kept in a locked filing cabinet in a secure office within the CLDT, separately from any interview data. In accordance with Bangor University procedures, anonymised data will be held securely for five years following the end of the project.

Data analysis:
Qualitative methodology provide detailed narratives and can provide greater understanding about human experiences (Denxin and Lincoln, 2005) as they enable rich descriptions from participants to be generated (Smith, 2008), and allow researchers to explore how participants make sense of their experiences, for example living with a chronic illness (Willig, 2008).

It is proposed that Interpretative Phenomenological Analysis (IPA; Smith, 1996) will be used to analyse the transcripts, which is particularly appropriate for understanding the "lived experience" of the participant, using a subjective and reflective process of interpretation. The inductive and interpretive procedures of IPA help the researcher develop an "inside perspective" on the topic being studied, whilst also providing an interpretation of what this means to the participant. IPA is phenomenological in that it aims to explore a person's perception or account of an event rather than producing an objective record of the event itself. IPA is also hermeneutic, in that it recognises the exploration of participants' experiences is also dependent on the researchers' interpretation. This methodology is in depth and meaning is central to IPA. The aim it to try and understand the content and complexity of the meanings rather than the frequency (Smith & Osborn, 2007).

IPA analysis of interview transcripts will follow a step-by-step approach (Smith & Osborn, 2007). The first stage of analysis begins with thoroughly reviewing the first transcript, making notes and describing the content. Following this, the next step is identification of themes, emerging patterns and commonalities and linking themes to reflect wider concepts or shared meanings. A summary table is created (for each transcript) with structured themes and illustrative quotes. With subsequent transcripts theme development continues and the clustering of themes to reflect wider concepts and shared understanding. This is a cyclical process and themes that emerged in later transcripts can be reviewed in earlier ones. The final stage of analysis is the write up, the themes to focus on will be decided upon, which will depend not necessarily on prevalence by also on richness. The themes will be translated into a narrative account where themes will be explained and illustrated with verbatim extracts.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☐ Design of the research

☐ Management of the research

☑ Undertaking the research

☐ Analysis of results

☑ Dissemination of findings

☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
Service users from Community Learning Disability Teams who have received DBT will be invited to participate in the research project.
Service users will be interviewed by the primary researcher.
Service users will not be involved in disseminating the findings themselves, but will be invited to receive feedback regarding the research findings.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

☐ Blood

☐ Cancer

☐ Cardiovascular

☐ Congenital Disorders

☐ Dementias and Neurodegenerative Diseases

☐ Diabetes

☐ Ear

☐ Eye

☐ Generic Health Relevance

☐ Infection

☐ Inflammatory and Immune System

☐ Injuries and Accidents

☑ Mental Health

☐ Metabolic and Endocrine

☐ Musculoskeletal

☐ Neurological

☐ Oral and Gastrointestinal

☐ Paediatrics

☐ Renal and Urogenital

☐ Reproductive Health and Childbirth

☐ Respiratory

☐ Skin

☐ Stroke

Gender: Male and female participants

Lower age limit: 18	Years
Upper age limit:	No upper age limit

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

•Participants must be assessed as having a learning disability and as such
currently open to a CLDT within North Wales.
•Participants must be over 18 years of age.
•Participants must be able to provide informed consent.
•Participants must have either completed, or be attending full programme DBT
(individual sessions and skills group).
•Participants currently enrolled in DBT must have completed a minimum of 2 months
full programme DBT.
•Participants who have completed DBT will be eligible to take part if they
finished attending DBT within the last 12 months.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

•Individuals who are unable to provide informed consent.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

    1. Total number of interventions/procedures to be received by each participant as part of the research protocol.

    2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?

    3. Average time taken per intervention/procedure (minutes, hours or days)

    4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Initial approach regarding the research	1	0	1hour	Potential participants will initially be approached by their lead clinician (either DBT or CLDT). Potential participants will be approached during their weekly DBT session or during an upcoming session with a CLDT clinician if they have recently completed DBT. The clinician will provide verbal information about the study and what participation would involve.
Given information sheets	1		2 days	When initially approached by their familiar clinician potential participants will also be provided with an information sheet about the study. All written information will be provided in an accessible format. Potential participants will then decide whether they would like to discuss the study further with the lead researcher. Potential participants will be made aware that meeting with the researcher will not mean that they are obliged to take part.
Request for further information/discussion about participation	1		5 mins	Potential participants will be required to return opt-in forms via e-mail or post (via a provided stamped addressed envelope) to the researcher if they would like to meet to hear more about the study and participation.
Meeting with researcher	1		1 hour	Potential participants will meet with the lead researcher to discuss the study in more detail and what participation will involve. The lead researcher will provided verbal and written information about the study (in an accessible format). Potential participants will be invited to ask questions about the study and participation.
Give consent	1		30 minutes	Researcher will assess capacity to consent using a protocol based on Arscott Dagnan & Kroese (1998). (See appendix).

If individuals are considered as having capacity to consent, the
researcher will gain informed consent to participate from all
participants. Written consent will be preferred, however if participants
are unable to provide written consent, they can provide verbal consent
recorded by the researcher.

Research interview	1	45-60minutes	Participants to give detailed description of their experiences of attending full programme DBT within a community learning disability service.

A21. How long do you expect each participant to be in the study in total?

From being sent information to being sent a summary of the findings, to some extent the participants will be involved
for a maximum of 18 months. However, participants will only actually be actively involved in the research process for
approximately 5 hours.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes
to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps
would be taken to minimise risks and burdens as far as possible.*

Individuals will be approached who have recently been in, or are currently in full programme DBT. This means that
they are likely to be currently experiencing some current difficulties which may be distressing for them. Additionally,
DBT treatment may be a difficult experience for some individuals. For this reason potential participants will be initially
approached by a familiar clinician. Potential participants will be informed about the research project and asked if they
would be interested in discussing the project further with the researcher. Potential participants will be made aware
that discussion with the researcher will not make them obliged to take part and reassured that their decision to take
part or not will not affect their current or future care. Participants will also be informed of their right to withdraw at any
time without explanation.

The interview may feel demanding for some individuals and participants may become distressed when discussing
their experiences, so the researcher will remain sensitive to the emotional state of the participant at all times and be
flexible in taking breaks throughout the interview.   The researcher is a trainee clinical psychologist and so has the
skills necessary to manage high levels of emotion and distress. Immediate distress will be addressed by the
researcher within the interview, and further support will be sought by the researcher for the participant should this be
required. Participants will be made aware of whom they should contact should they feel distressed (typically their
lead clinician).
Additionally, the researcher will inform the participants' lead clinician if they become particularly distressed.
Participation will be drawn to a close should participants experience significant distress and feel unable or unwilling
to continue. Participants will be fully debriefed following the interview and be given contact details of the research
team, so they are able to contact them if they feel they need additional support.

Participants may feel reluctant to given honest reports of their experiences, particularly if discussing negative
experiences. The verbal and written information regarding the study will make it clear that the research will be
anonymous and that their participation in the study will not affect their current or future care. This will be explained
again at the start of the interview. However, limits of confidentiality will also be outlined and it would be made clear
that if the participant was to disclose anything that might indicate risk to themselves or others this information will be
passed on to the appropriate person(s).

The anonymity of the data could be compromised by the fact that Dr Carmel Harrison, member of the research team,
may know or work with the participants and may be involved in the analysis of the transcripts. The researcher will
seek to minimise this by removing any identifiable information and making specific words more general in any
passages before sharing with other members of the research team during the analysis stage.

**A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or
upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

⦿ Yes   ○ No

If Yes, please give details of procedures in place to deal with these issues:

Participants will have either recently received, or be currently receiving DBT. This means that participants are likely to
be experiencing/have recently experienced some emotional or relational difficulties, which may be distressing for
them. Additionally, DBT sessions may be demanding and/or a difficult experience for some participants. Thus,

discussing their experiences of DBT, is may involve recalling some difficult experiences and emotions for participants. The researcher will allow participants to take their time and either come back to or leave issues that cause distress.

If a participant were to become distressed at any point during the interview, they would be given the option for interviewing to be stopped. Any immediate distress will be addressed by the researcher, a trainee clinical psychologist who has the skills necessary to manage high levels of emotion and distress. The researcher will seek further support for the participant should this be required. Participants will be made aware of whom they should contact should they feel distressed (typically their lead clinician). Additionally, the researcher will inform the participants' lead clinician if they become particularly distressed. Participation will be drawn to a close should participants experience significant distress and feel unable or unwilling to continue. Participants will be fully debriefed following the interview and be given contact details of the research team, so they are able to contact them if they feel they need additional support.

There is a possibility that during the interview participants could disclose something that may raise concern about themselves or others. The limits of confidentiality will be clearly explained to the participants prior to the interviews. Should any participant disclose anything that might indicate risk to themselves or others this information will be passed on to the appropriate person(s).

A24. What is the potential for benefit to research participants?

Participants may find the research beneficial in enabling an opportunity to reflect on their experience of services. Participants may recall some positive skills acquired during their DBT sessions which may be helpful to them during their current situations.

Additionally, individuals with a learning disability are not often asked about their opinions and experiences; this opportunity may allow them to foster a sense of feeling valued.

Participants will be contributing to the knowledge base of DBT for individuals with learning disabilities, which will further enhance the understanding of the effectiveness of DBT among this population. Enhanced understanding will enable services to ensure that they are offering interventions appropriate and efficacious for individuals with learning disabilities. Essentially, participants will contribute to informing and augmenting DBT interventions in order to enhance treatment outcomes for current and future service users.

A26. What are the potential risks for the researchers themselves? *(if any)*

Lone working, the researcher may be required to travel independently across North Wales to conduct interviews. The researcher will abide by the NHS lone working policy, contacting their supervisor on arrival and on departing sites.

Managing the emotional and concentration demands of conducting in-depth interviews. The researcher will be mindful of these demands, notifying the participant if breaks are appropriate either for them or the researcher and seeking appropriate supervision.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Firstly, community learning disability DBT team members across North Wales will be contacted via the research supervisor and arrangements will be made for the researcher to attend a meeting to introduce the research project and what it would involve. DBT clinicians will be made aware of the inclusion and exclusion criteria, and will be asked to identify potential participants from their caseload. DBT clinicians will also be asked to identify any potential participants who may have completed DBT recently, and therefore may not currently be on their caseload but remain open to a clinician within the CLDT.

Any potential participants who are currently in DBT will be approached by their DBT clinician during their weekly DBT session. Any potential participants who have recently completed DBT will be approached either by their former DBT clinician or by their lead clinician within the CLDT.

Clinicians will discuss the research study and what participation will involve, and ask the potential participants if they would like to meet with the researcher to further discuss the research. Clinicians will provide potential participants with an accessible information sheet and opt-in form. Potential participants will be made aware that meeting with the researcher to gain some further information will not mean that they have to participate. Should potential participants be interested in hearing more about the research and meeting with the researcher, they will be required to complete the opt-in form provided and return it either via e-mail or via post (in a provided stamped addressed envelope) to the researcher. The identity of any potential participants that chose not to participate will therefore not be known to the researcher.

Interview data will be transcribed by the primary researcher and all identifying information removed. The primary researcher will assign each participant a research identification number and information will therefore be anonymised. Any personal information or identifiers required (e.g. contact information to communicate feedback from the project) will be stored separate from any data. All transcriptions of data will be password protected. All audio recordings will be deleted following transcription. Any hard copies including participant information such as interview schedule, list of participants will be kept in a locked filing cabinet at the CLDT. Once the project is completed, we aim to delete all data in accordance with Bangor University and Protection policies.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

◯ Yes   ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

◯ Yes   ◉ No

A29. How and by whom will potential participants first be approached?

Firstly, community learning disability DBT team members across North Wales will be contacted via the research supervisor and arrangements will be made for the researcher to attend a meeting to introduce the research project and what it would involve. DBT clinicians will be made aware of the inclusion and exclusion criteria, and will be asked to identify potential participants from their caseload. DBT clinicians will also be asked to identify any potential participants who may have completed DBT recently, and therefore may not currently be on their caseload but remain open to a clinician within the CLDT.

Any potential participants who are currently in DBT will be approached by their DBT clinician during their weekly DBT session. Any potential participants who have recently completed DBT will be approached either by their former DBT clinician or by their lead clinician within the CLDT.

Clinicians will discuss the research study and what participation will involve, and ask the potential participants if they would like to meet with the researcher to further discuss the research. Clinicians will provide potential participants with an accessible information sheet and opt-in form. Potential participants will be made aware that meeting with the researcher to gain some further information will not mean that they have to participate. Should potential participants be interested in hearing more about the research and meeting with the researcher, they will be required to complete the opt-in form provided and return it either via e-mail or via post (in a provided stamped addressed envelope) to the researcher. The identity of any potential participants that chose not to participate will therefore not be known to the researcher.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes   ◯ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material).

Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Potential participants will be given detailed information regarding the study verbally by their lead clinician, as well as through a detailed, accessible information sheet. Potential participants will also meet with the lead researcher who will introduce the study and explain in detail what participation will involve. A second, more detailed participant information sheet will be proved at this point. Participants will not be required to decide during the meeting with the lead researcher whether they wish to participate, they will be given the chance to go away and think further about participating.

Informed consent will be obtained by the researcher, who is a trainee clinical psychologist and experienced in obtaining informed consent in their clinical work. Capacity to consent will be assessed by the researcher by following a protocol based on a procedure followed by Arscott, Dagnan & Kroese (1998). See attached documents. Participants who are deemed not to have capacity to provide full informed consent will be withdrawn from the sample. Written informed consent will be the preferred option, however where participants are unable to provide written consent, verbal consent will be taken and recorded by the researcher.

Collaboratively, a suitable time and venue to conduct the interview will be arranged.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes   ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

From first being approached by their lead clinician, potential participants will be given three weeks to decide whether to participate in the study. However, the researcher aims to cease recruitment by March 2018 to allow sufficient time to write up the project.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

All information sheets, opt-in form and consent forms will be made available in an accessible "easy read" format.

Additionally all information sheets and opt-in forms will be provided to potential participants by their lead clinician, who will talk through the information provided with them. Consent forms will be provided by the primary researcher who will discuss these in person with the potential participant.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

All information sheets, opt in forms and consent forms will be made available in English and Welsh.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

◉ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

☐ Access to medical records by those outside the direct healthcare team

☐ Access to social care records by those outside the direct social care team

☐ Electronic transfer by magnetic or optical media, email or computer networks

☐ Sharing of personal data with other organisations

☐ Export of personal data outside the EEA

☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers

☑ Publication of direct quotations from respondents

☐ Publication of data that might allow identification of individuals

☑ Use of audio/visual recording devices

☐ Storage of personal data on any of the following:

    ☐ Manual files (includes paper or film)

    ☑ NHS computers

    ☑ Social Care Service computers

    ☐ Home or other personal computers

    ☐ University computers

    ☐ Private company computers

    ☐ Laptop computers

Further details:
The primary researcher will contact potential participants using the contact information provided on the opt-in forms. Interviews may be conducted at participants' home addresses if this is the preferred option. Where participants have indicated that they would like feedback from the study, the primary researcher will disseminate the research findings using the contact information provided by participants.

Anonymised direct quotations may be used in the write up of the study. This will be clearly outlined in the participant information sheet and a separate tick box will be included in the consent form to indicate whether participants consent to this.

A digital audio recording of the interview will need to be made for the purpose of the research. This will be transferred to an NHS/Social Services computer upon completion of the interview. Identifiable information will be changed during

the course of transcription. Original audio recordings of the interview will be destroyed following transcription/ Transcripts of audio records will be stored on an encrypted stick provided by NWCPP. All information, digital recorder, audio recordings will be transported via a locked brief case.

A37. Please describe the physical security arrangements for storage of personal data during the study?

All paper information regarding participants will be kept in a locked cabinet at Flintshire CLDT, separately to any interview data.
Participants will each be assigned a number and this will be used to identify participant information.
A document linking participants names to their assigned numbers will be held securely at Flintshire CLDT in a locked cabinet and stored on a password protected document on the researcher's personal NHS or Social Services drive. Information/equipment (digital recorder) will be transported via a locked briefcase.

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All names, places and specific information relating to participants will be anonymised to avoid any identification. Once the lead clinician or researcher has spoken to potential participants about the research, other colleagues will have no knowledge of who consents to participate, or what information individual participants disclose.

Any identifiers located in the recordings of the interview will be anonymised with the use of pseudonyms. Any information that is not considered essential (e.g. names of places, towns, hospitals) in the interviews will be changed and/or anonymised. Recordings of interviews will be deleted once transcription is complete.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The primary researcher will have access to the contact information provided by the participants on their opt-in and consent forms. The primary researcher will require participant's preferred contact details (e.g. telephone number/email address) for the researcher to initially arrange to meet to discuss the research. Additionally, the primary researcher will require the participant's home address should the participant prefer to complete the interview at their home. Finally, contact details (e.g. address, email address) of participants who indicate that they would like to receive written feedback will be needed.

All such contact details will be kept in a locked cabinet at Flintshire CLDT and destroyed after feedback has been sent. Contact details will be destroyed after the interview should participants decline to receive any feedback.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data will be generated within the qualitative interviews, either within a CLDT base or within the participants' own home. Data will be transcribed in full and made confidential on an NHS or Social Services computer by the researcher. Anonymised transcription will be transferred to an encrypted USB stick for analysis. Supervision will be required for this process which will be conducted by Dr Gemma Griffith and Dr Carmel Harrison. Data requiring additional input from the supervisory team will be transported using an encrypted USB stick and only necessary passages will be transported.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Miss	Emma Louise	Woolfall
Post	Trainee Clinical Psychologist		
Qualifications	BSc Psychology (1st Class).		
Work Address	North Wales Clinical Psychology Programme		
	Brigantia Building, Bangor University,		

	Bangor, Gwynedd
Post Code	LL57 2DG
Work Email	psp6c2@bangor.ac.uk
Work Telephone	01248388365
Fax	

A43. How long will personal data be stored or accessed after the study has ended?

◉ Less than 3 months

◯ 3 – 6 months

◯ 6 – 12 months

◯ 12 months – 3 years

◯ Over 3 years

A44. For how long will you store research data generated by the study?

Years: 5
Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be stored, who will have access and the arrangements to ensure security.*

Digital and paper copies of transcribed data will be stored at Flintshire CLDT in a locked filing cabinet until the project has been completed. In accordance with Bangor University procedures, anonymised data will be stored for five years after thesis submission to be available for scrutiny. The academic supervisors will have access to the data and ensure it is adequately stored for the five years and destroyed after this time.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◯ Yes   ◉ No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

◯ Yes   ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

◯ Yes   ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes   ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes   ◉ No

Please give details, or justify if not registering the research.
This project will be approved by the local R&D department.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals

☐ Internal report

☑ Conference presentation

☐ Publication on website

☐ Other publication

☐ Submission to regulatory authorities

☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☑ Other (please specify)

Participants will receive an information leaflet outlining the findings of the study and how they will be used in clinical practice.

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Any quotes or examples used in disseminating findings will be checked for anonymity, ensuring no personal identifiable information is disseminated. This process will start with the transcription and anonymisation of audio recordings.

A53. Will you inform participants of the results?

◉ Yes   ○ No

Please give details of how you will inform participants or justify if not doing so.
Participants will be asked to indicate if they would like to receive feedback of the results.
Participants who indicate that they would like to receive feedback will be sent a one page summary, written in an accessible format, upon completion of the research.
The researcher will also aim to arrange to provide a brief presentation on the results to each of the DBT teams involved in the study.

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5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review

☐ Review within a company

☐ Review within a multi-centre research group

☑ Review within the Chief Investigator's institution or host organisation

☑ Review within the research team

☑ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The proposal for this study has been reviewed and approved by the North Wales Clinical Psychology Programme at Bangor University. The research team are a group independent from the researcher who will analyse the viability of the research proposal.
The proposal has also been reviewed by the School of Psychology Ethics team.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 8

Total international sample size (including UK):

Total in European Economic Area:

Further details:

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The sample size was calculated on the available sample of the DBT teams within North Wales Community Learning Disability Teams, and following discussion with research supervisors. We accounted for an estimated 30-40% uptake rate of participants for this qualitative project. In addition, time restrictions imposed on the primary researcher to complete the project were taken into account. Additionally, in line with interpretative phenomenological analysis, approximately 6-10 participants are required for doctoral level qualitative studies (Smith et al., 2010). Ethical approval for 8 participants is being sought for this study to account for the fact that some homogeneity of the sample (recommended for IPA) will be compromised by the recruitment of participants from different backgrounds, so as to ensure a rich data set.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

This study proposes to employ a qualitative approach, as the study aims to explore an area that has not been widely researched. The proposed methodology is Interpretative Phenomenological Analysis (IPA; Smith, 1996). IPA allows understanding of the participants lived experiences and how participants themselves make sense of their experiences. This methodology allows flexibility in the interview schedule, which suggest data collection will capture the richest and most important aspects of service users' experiences of DBT.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Carmel	Harrison
Post	Senior Clinical Psychologist		
Qualifications	DClinPsy		
Employer	Bestsi Cadwaladr University Health Board		
Work Address	Flintshire Community Learning Disability Team		
	County Hall		
	Mold, Flintshire		
Post Code	CH7 6NN		
Telephone	01352701081		
Fax			
Mobile			
Work Email	carmel.harrison@flintshire.gov.uk		

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: ○ NHS or HSC care organisation

⦿ Academic

○ Pharmaceutical industry

○ Medical device industry

○ Local Authority

○ Other social care provider (including voluntary sector or private organisation)

○ Other

Commercial status:

If Other, please specify:

Contact person

Name of organisation	Bangor University
Given name	Hefin
Family name	Francis
Address	Brigantia Building, School of Psychology, Penrallt Road,
Town/city	Bangor
Post code	LL57 2AS
Country	UNITED KINGDOM
Telephone	01248388339
Fax	01248382599
E-mail	h.francis@bangor.ac.uk

Is the sponsor based outside the UK?
○ Yes   ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders

☐ External funding application to one or more funders in progress

☑ No application for external funding will be made

What type of research project is this?

○ Standalone project

○ Project that is part of a programme grant

○ Project that is part of a Centre grant

◉ Project that is part of a fellowship/ personal award/ research training award

○ Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes   ◉ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes   ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Ms Rossela Roberts
Organisation	Betsi Cadwaladr University Health Board
Address	Research & Development, Clinical Academic Office, Clinical School
	Ysbyty Gwynedd, bangor, Gwynedd
Post Code	LL57 2PW
Work Email	rossela.roberts@wales.nhs.uk
Telephone	01248384877

| Fax |
| Mobile |

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

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A69-1. How long do you expect the study to last in the UK?

Planned start date: 04/09/2017

Planned end date: 01/10/2018

Total duration:

Years: 1 Months: 0 Days: 28

A71-1. Is this study?

◉ Single centre

◯ Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

☐ England

☐ Scotland

☑ Wales

☐ Northern Ireland

☐ Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?

◯ Yes   ◉ No

A72. Which organisations in the UK will host the research? *Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

☐ NHS organisations in England

☐ NHS organisations in Wales

☐ NHS organisations in Scotland

☐ HSC organisations in Northern Ireland

☐ GP practices in England

☐ GP practices in Wales

☐ GP practices in Scotland

☐ GP practices in Northern Ireland

☑ Joint health and social care agencies (eg   1
community mental health teams)

☐ Local authorities

☐ Phase 1 trial units

☐ Prison establishments

☐ Probation areas

☐ Independent (private or voluntary sector)
organisations

☐ Educational establishments

☐ Independent research units

☐ Other (give details)

Total UK sites in study: 1

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

◯ Yes   ⦿ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The supervisory team, the North Wales Clinical Psychology Programme, myself and the Bangor University School of
Psychology Ethics Department will take responsibility for the conduct of the research. Research Governance
Frameworks will be adhered to and monitored if necessary, by the Betsi Cadwaladr University Health Board NHS
Department. The primary researcher will endeavour to have monthly supervision to aid monitoring progress of the
study and conduct of the research carried out.

A76. Insurance/ indemnity to meet potential legal liabilities

*Note: In this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care
(HSC) in Northern Ireland*

**A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the
sponsor(s) for harm to participants arising from the management of the research?** *Please tick box(es) as applicable.*

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes.
Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the
arrangements and provide evidence.*

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the
management of the research.

Please enclose a copy of relevant documents.

**A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the
sponsor(s) or employer(s) for harm to participants arising from the design of the research?** *Please tick box(es) as
applicable.*

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided
through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol
authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the design of
the research.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the <u>conduct</u> of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes ◉ No ○ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For further information please refer to guidance.*

Investigator identifier	Research site		Investigator Name	
IN1	⊙ NHS site			
	○ Non-NHS site		Forename	Carmel
			Middle name	
	Country: Wales		Family name	Harrison
			Email	carmel.harrison@flintshire.gov.uk
			Qualification (MD...)	BSc (Hons); DClinPsy
	Institution name	Betsi Cadwaladr University Health Board(NHS Wales)	Country	UNITED KINGDOM
	Department name	Flintshire Community Learning Disability Team		
	Street address	County Hall, Raikes Lane,		
	Town/city	Mold		
	Post Code	CH7 6NN		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

   - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
   - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
   - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
   - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
   - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

◉ Chief Investigator

◯ Sponsor

◯ Study co-ordinator

◯ Student

◯ Other – please give details

◯ None

Access to application for training purposes *(Not applicable for R&D Forms)*
Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Emma Louise Woolfall on 22/09/2017 10:22.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	Betsi Cadwaladr University Health Board
Email:	louisewoolfall@gmail.com

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Mr Hefin Francis on 21/09/2017 09:42.

Job Title/Post:	School Manager for Psychology
Organisation:	Bangor University
Email:	h.francis@bangor.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Gemma Griffith on 21/09/2017 12:29.

Job Title/Post:	lecturer
Organisation:	bangor uni
Email:	g.m.griffith@bangor.ac.uk

149

Appendix 4: Research Ethics Committee Favourable Opinion

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Mailing address: Health and Care
Research Wales Support Centre
Castlebridge 4
15-19 Cowbridge Road East
Cardiff
CF11 9AB

Telephone: 02920 785736
07949 951024

Email: rossela.roberts@wales.nhs.uk norbert.ciumageanu@wales.nhs.uk Website :
www.hra.nhs.uk 25 October 2017

Miss Emma Louise Woolfall

Trainee Clinical Psychologist

North Wales Clinical Psychology Programme
School of Psychology, Bangor University

Bangor

LL57 2DG

Dear Miss Woolfall,

Study title:	**Service user experiences of Dialectical Behaviour Therapy within adult community learning disability teams: A qualitative exploration.**
REC reference:	**17/WA/0321**
Protocol number:	**NA**
IRAS project ID:	**230422**

The Research Ethics Committee reviewed the above application at the meeting held on
19 October 2017.   Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

Recommendations:

The Committee recommended that in the Participant Information Sheet, in paragraph "What if I have questions about the study?" the sentence "you can phone or ask somebody to phone Louise" could be rephrased to clarify that this is not a direct number and participants will not automatically reach the researcher:"[...] phone the Community LD team and ask for

Louise – the phone number is [...]"

Similarly, the picture of the audio-cassette/tape could be replaced with a microphone or similar contemporaneous illustration.

This is a recommendation only and not a condition of the favourable opinion.

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission 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 Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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 clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Ethical issues raised by the Committee in private discussion, together with responses given by you when invited to join the meeting

The Chairman welcomed you and introduced the Committee members.
The following issues were discussed:

Social or scientific value; scientific design and conduct of the study
The Committee congratulated the applicant on for a very well presented application for a study with a highly appropriate research question.

The Committee discussed whether the design and methodology makes use of accepted scientific principles and methods (including statistical techniques)to produce reliable and valid data – and queried the operational definition of 'recently finished DBT' for the purpose of the study.

You clarified that patients who would have had 2 rounds of DBT and finished the intervention at some point in the last 12 months will be eligible to take part.

The Committee concluded that the conduct of the study is appropriately described in the protocol, the study design robust and the proposed analysis adequate to answer the research question.

Recruitment arrangements and access to health information; fair participant selection The Committee discussed the recruitment method and queried whether asking the lead clinician to approach patients may be coercive to the patient in the instance where the clinician had also delivered the intervention.

You clarified that the lead clinician might be the consultant, the therapist, a nurse or member of the wider care team. The study was presented to the clinical care team who advised on eligible number of patients receiving DBT; it is envisaged to rely on their clinical insight into the patient's condition to determine eligibility.

The Committee was satisfied that the selection of participants has taken into account the patients' clinical care, participants will be recruited fairly and sufficient details are provided in the protocol regarding the inclusion and exclusion criteria.

Informed Consent process and the adequacy and completeness of participant information The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. The language used is understandable to the research participants, the information is clear as to what the participant consents to, and there is no inducement or coercion. The Committee agreed that the procedures described in the protocol have been adequately addressed in the Information Sheet, but queried whether the telephone number listed is a direct line.

You clarified that it is the departmental phone number.

The Committee recommended that this is made clear on the Participant Information Sheet. Similarly, the picture of the audio-cassette/tape could be replaced with a microphone or similar contemporaneous illustration, for the benefit of younger participants.

The Committee thanked you for your availability to speak to this submission and gave you an opportunity to ask questions. You did not raise any issues.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

No ethical issues were raised in relation to

• Favourable risk benefit ratio; anticipated benefit/risks for research participants
• Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality • Suitability of the applicant and supporting staff • Independent review • Suitability of supporting information • Other study procedures • Other general comments missing information/ typographical errors/ application errors/ • Suitability of the study summary

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of indemnity insurance for Bangor University]		15 July 2017
Interview schedules or topic guides for participants [Interview schedule V1]	1	18 September 2017
IRAS Application Form [IRAS_Form_22092017]		22 September 2017
Letters of invitation to participant [Participant info sheet 1]	1	18 September 2017
Other [Verbal consent form]	1	18 September 2017
Other [Functional assessment of capacity to consent]	1	18 September 2017
Other [Information for recruiting clinicians]	1	18 September 2017
Other [Participant opt in form]	1	18 September 2017
Participant consent form [Written consent form]	1	18 September 2017
Participant information sheet (PIS) [Participant info sheet 2]	1	18 September 2017
Research protocol or project proposal [Research protocol]	1	28 September 2017
Summary CV for Chief Investigator (CI) [CV Louise Woolfall]		18 September 2017
Summary CV for supervisor (student research) [CV for research supervisor]	1	19 September 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol Diagram]	1	18 September 2017

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

No declarations of interest were made in relation to this application.

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.

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:

155

- 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

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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: http://www.hra.nhs.uk/about-thehra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/WA/0321	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Rossela Roberts

Dr. Ros, ela Roberts, Research Ethics Service Manager

On behalf of

**Dr Philip Wayman White, MBChB,
FRSM General Practitioner, Chair
Wales REC 5**

E-mail: rossela.roberts@wales.nhs.uk

Enclosures: *List of names and professions of members who were present at
                  the meeting and those who submitted written comments
                  "After ethical review – guidance for researchers"*

Copy to: *Sponsor: Hefin Francis, Bangor University
                  R&D Office: Miss Debra Slater, Betsi Cadwaladr University
                  Health Board*

Wales REC 5

Attendance at Committee meeting on 19 October 2017

Committee Members

Name	Profession	Capacity	Present
Dr Karen BE Addy	Clinical Neuropsychologist	Expert	Yes
Dr Swapna Alexander	Consultant Physician	Expert	Yes
Mrs Kathryn Chester	Research Nurse	Expert	Yes
Ms Geraldine Jenson	Retired College Vice-Principal	Lay +	Yes
Mr David Rhys Jones	Retired Teacher	Lay +	No
Mr Eliezer Lichtenstein	Student	Lay +	Yes
Dr Mark Lord	Consultant Pathologist	Expert	No
Dr Pamela A Martin-Forbes	Clinical Studies Officer	Expert	Yes
Dr Paul G Mullins	Reader, Senior MRI Physicist	Lay +	Yes
Mr Vishwanath Puranik	Consultant ENT Surgeon	Expert	Yes
Mrs Lynn C Roberts	Matron, Emergency Department	Expert	Yes
Dr Judith L Roberts	Lecturer, Clinical Psychologist	Expert	Yes
Dr Jason D Walker	Consultant Anaesthetist (Vice-Chair)	Expert	No
Dr Philip W White	General Practitioner (Chairman)	Expert	No
Ms Sydna A Williams	Retired Lecturer / College Principal	Lay +	Yes

In attendance

Name	Position (or reason for attending)
Dr Rossela Roberts	Research Ethics Service Manager

Appendix 5: Research and Development (R&D) approval letter

GIG CYMRU **NHS** WALES | Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board	**Panel Arolygu Mewnol Y&D** **R&D Internal Review Panel**

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Miss Emma Louise Woolfall   Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP

School of Psychology, Bangor North Wales Clinical Psychology Programme   Email:

Debra.slater@wales.nhs.uksion.lewis@wales.nhs.ukTel/Fax: 01248 384 877

Gwynedd

LL57 2DG   psp6c2@bangor.ac.uk

22 November 2017

Dear Miss Woolfall,

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title	Service user experiences of Dialectical Behaviour Therapy within adult community learning disability teams: A qualitative exploration.
IRAS reference	230422
REC reference	17/WA/0321

Thank you for submitting your R&D application and supporting documents. The above research project was reviewed at BCUHB by the R&D Internal Review Panel (IRP) proportionate review (PR) process.

The Panel is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application. *A full list of documents included in the review is attached as an appendix.*

The R&D Office, on behalf of the Internal Review Panel, is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please go to: http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at: http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571 and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.
Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact debra.slater@wales.nhs.uk

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If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Panel, I would like to take this opportunity to wish you every success with your research.

Yours sincerely,

Miss Debra Slater

Research Governance Officer

 Copy to:

Principal Investigator: Ms Carmel Harrison
Senior Clinical Psychologist
Betsi Cadwaladr University Health Board
Flintshire Learning Disability Service
County Hall,
Mold, Flintshire
CH7 6NN   carmel.harrison@flintshire.gov.uk

Sponsor: Hefin Francis

Brigantia Building, School of Psychology, Penrallt Road, Bangor
LL57 2AS   h.francis@bangor.ac.uk

Academic Supervisor: Dr Gemma Griffith
Centre for Mindfulness Research and Practice Bangor
University,
Bangor, Gwynedd,
LL57 2DG   g.m.griffith@bangor.ac.uk

Information for clinicians

DIALECTICAL BEHAVIOUR THERAPY: service user experiences

Do you know a service user who has recently completed or is currently attending DBT?

If so, they may be eligible to take part in our research study.

Why is the research being carried out?

Dialectical Behaviour Therapy (DBT) is a psychological intervention that has been shown to be effective in reducing emotional distress, para-suicidality and self-harming behaviours among the general population. More recently DBT has been adapted to enable individuals with a learning disability to effectively access the intervention too. Currently, there is very little research which has investigated the effectiveness of adapted DBT among individuals with a learning disability.

What are the study aims?

The aim of this study is to find out what service users' experiences are of attending adapted DBT. Finding out about service users' experiences can help us to work out what really helps and what is less helpful, to ensure that we are delivering interventions that work for our service users.

The study will form part of a Doctorate of Clinical Psychology thesis for Louise Woolfall, who is studying at Bangor University. She is being supervised by Dr Carmel Harrison who is a Senior Clinical Psychologist at Flintshire Community Learning Disability Team and Dr Gemma Griffith from Bangor University who has a PhD in Psychology and is a keen researcher in the field of learning disabilities.

What would be expected of me?

Your help in recruiting participants who have recently completed or are currently attending DBT would be extremely valuable.

This would involve mentioning the research to people that you're working with who may like to be involved. If they are interested, you would provide them with an "I'm interested" form (attached) that will be returned to the research team, who will then contact with the service user to explain more about the study.

How would I know if a service user I'm working with may be suitable?

Service users may be considered eligible for inclusion if the answers are 'yes' to the following questions:

- Is the person currently open to a community learning disability team?
- Are they 18 years or over?
- Have they completed full programme DBT within the last 12 months OR are they currently in full programme DBT?
- If they are currently in full programme DBT have they completed a minimum of 2 months?
- Can they consent to participate in the research?

What do I need to do?

If you know somebody who may be interested, simply complete the "I'm interested form" (attached to this leaflet) with the service user and return to the research team in the stamped addressed envelope that is included in this information pack.

What if I have questions about the study?

If you have any questions you can email me at **psp6c2@bangor.ac.uk**

Complaints

If you have any complaints about this research, please contact:

For an NHS complaint: Concerns Team
                          Betsi Cadwaladr University Health Board
                          Ysbyty Gwynedd
                          Bangor
                          Gwynedd
                          LL57 2PW
                          Email: ConcernsTeam.bcu@wales.nhs.uk
                          Tel: 01248 384194

For a University complaint: Hefin Francis (School manager)

                    School of Psychology

                    Adeiliad Brigantia

                    Penrallt Road

                    Gwynedd

                    LL57 2AS

                    Email: h.francis@bangor.ac.uk

                    Tel: 01248 388339

Participant information sheet I

What is the research about?

About me

My name is Louise Woolfall. I'm doing some research and would like to ask for your help.

What is research?

Research is finding out about something in an organised way.

Why have I been asked to take part?

You have been asked to take part because you have attended DBT, to help learn some ways of managing big emotions and relationships.

What is the research about?

The research will find out what you think about DBT. Louise would like to find out about what you think is helpful and unhelpful about DBT. Louise would like to meet up to talk to you about DBT.

This will help us to try and run DBT in the most helpful way in the future.

164

What if I am not doing DBT any more?

That is ok, you can still take part if you have been receiving DBT in the last year.

What should I do if I want to take part?

- If you would like to take part, then please fill in the **"I'm interested"** form, which is included in this pack. This just means that you say it is OK for Louise to get in touch with you and that you would like to find out more.
- Then, put the **"I'm interested"** form in the envelope that is in this information pack (it already has the right address on it). Then post the envelope.
- When Louise sees your form, she will phone or e-mail you to arrange a time and place to meet that is best for you. This could be in your home or in a clinic close to where you live.

Do I have to take part?

- If you do not want to meet and talk with Louise, just say no.
- If you say yes, but then change your mind, that is OK too.
- This will not affect the way you are treated now or in the future.

Would you like to take part in the research?

It is up to you to decide if you would like to take part. You can have some time to think about it and talk to somebody you know about it.

What if I have questions about the study?

If you have any question you can e-mail or ask somebody to e-mail Louise – her e-mail address is: psp6c2@bangor.ac.uk

Or you can phone or ask somebody to phone Louise – her phone number is: **01352 701081.**

This is the phone number for Flintshire Learning Disability Team. You can leave Louise a message if she is not there and she will get back to you.

Complaints

If you have any complaints about this research, please contact:

Hefin Francis (School Manager)

The School of Psychology, Bangor University,

Pen yr Allt Road,

Bangor,

Gwynedd,

LL57 2AS.

Phone number: 01248 388339

"I'm Interested" Form

I would like to find out more about the research

Please get in touch to tell me more

Name:..

Length of time in DBT: ....

Start/complete date (if applicable): ....

Address:..

....

Email address: ....

Telephone number: ....

Signed: ……………………………………………

Date: …………………………………………

Participant information sheet II

Thank you for posting the "I'm interested" form and saying that you would like to hear more about the research.

Here's a reminder of what the research is about:

Louise's research will find out what you think about DBT. Louise would like to meet up to talk to you about DBT. She will ask you questions about:

- What is DBT
- What is it like doing DBT
- What you like about DBT
- What you don't like about DBT
- What is helpful about DBT
- What is unhelpful about DBT
- Does DBT help you

What will I have to do?

Louise will arrange a time to meet that is best for you. This can either be at your home or at the learning disability team base. Louise will only ask you to meet up once.

You will meet and talk about DBT. Louise will ask you some questions and you will be able to tell her anything you want to tell her about DBT.

Louise would like to record your meeting so that she can listen again afterwards. This will only record your voices, not your faces.

✗ If there are any questions you do not want to answer, that is ok, just tell Louise that you do not want to answer that question.

When you meet it will probably take about one hour.

What will happen to my voice recording?

After your chat about DBT Louise will change the voice recording into a written version of what you said. In the written version your real name will NOT be used. Louise will remove all information which might mean that people could tell that it was you.

This will then be kept in a safe place where only the research team can see it.

Louise will then delete the voice recording.

What will happen to my information?

The information that you give will be written in a report at the end. Your real name will NOT be used in any of the reports, so nobody except Louise would know who you were.

Whatever you say will not be shared with anybody outside the research team. But, if you tell Louise something that makes her worried about you or other people (like abuse), then she may need to talk about this with other people, such as the police or social services, to make sure that you and other people are safe.

Will I find out what the research told us?

Yes. After the research has finished, Louise will send you a letter in the post to tell you what you and other people thought about DBT.

What happens if I get upset because of talking about DBT or how I feel or if it makes me feel worse?

If you became upset during our meeting then you would be able to stop and take a break until you feel better.

It would be OK to stop the meeting and not carry on if it made you upset.

You would be able to get in touch with somebody you know from the learning disabilities team to help you if you became upset.

Can I bring somebody with me?

Yes, you can have somebody who you want with you during the meeting. But it is important that they do not help you answer the questions, we are interested in what YOU think about DBT.

Do I still have to take part?

- If you do not want to take part, just say no.
- If you say yes, but then change your mind, that is OK too.
- This will not affect the way that you are treated now or in the future.

Would you like to take part in the research?

It is up to you to decide if you would like to take part. You can have some time to think about it and talk to somebody you know.

What if I have questions about the study?

If you have any question you can e-mail or ask somebody to e-mail Louise – her e-mail address is: psp6c2@bangor.ac.uk

Or you can phone or ask somebody to phone Louise – her phone number is **01352 701081.**

This is the phone number for Flintshire Learning Disability Team. You can leave Louise a message if she is not there and she will get back to you.

Complaints

If you have any complaints about this research, please contact:

Hefin Francis (School Manager)

The School of Psychology, Bangor University,

Pen yr Allt Road,

Bangor,

Gwynedd,

LL57 2AS.

Phone number: 01248 388339

Appendix 10: Functional assessment of capacity to consent

Appendix: Guidelines for the Functional Assessment of Capacity

Diagnostic threshold

The Mental Capacity Act (2005) is a law which applies to all individuals aged 16 and over. The Act is designed to promote and safeguard decision-making within a legal framework; it aims to empower people to make decisions for themselves where possible and protect people who lack capacity.

The Act stipulates that a person may be deemed as lacking capacity in relation to a specific matter, if at that time they are unable to make a decision in relation to that matter, because of an impairment of, or a disturbance in the functioning of the mind of brain (Mental Health Act, 2005).

The Act acknowledges that if there is an established diagnosis of mental illness, intellectual disability or some other conditions, then this is sufficient to confirm "impairment or disturbance of the mind".

The Act (section 3) considers that an individual is unable to make their own decision if they cannot do one or more of the following things:

1. **Understand the information**
   The assessor is required to help the person understand the information relevant to the decision. Information should be presented in a clear and simple way or with the use of visual aids. Cultural and linguistic considerations should be included and family, friends, carers or support staff of the person being assessed should be used to assist the process

2. **Retain the information long enough to make the decision**
   Information only needs to be held in the mind of the person long enough to make the decision.

3. **Use or weight up the information**
   Some people can understand the information, but an impairment stops them from using it. Whereas others may make a decision without understanding it. A person capable of using or weighing the information would also need to demonstrate that they could see the consequences of making, or failing to make, that decision.

4. **Communicate their decision**
   Communication can be whatever the assessor accepts. Assessors should consider using specialist workers to assist in communication (for sensory impairment etc).

Protocol for Assessing Capacity to consent

Read the information sheet once to/along with the potential participant, then say:

"To take part in the research I need to be sure you understand what I am asking you to do. If it is ok, I will just ask you some questions about what we have just read"

Questions

1. Read the following part of the information sheet: *"Louise's research will find out what you think about DBT. Louise would like to meet up to talk to you about DBT. She will ask you questions about: What is DBT, What is it like doing DBT, what you like/don't like about DBT. What is helpful/unhelpful about DBT, does DBT help you?"*.

Ask the potential participant: ***"Why do I want to meet you and ask you some questions?"***

Score 2 for a clear and accurate answer such as: "*To find out what I think about DBT"* OR *"To find out what it is like doing DBT"* OR *"To find out what is good and/or bad about DBT"*

Score 1 if the individual gives an answer similar to but less clear than the above response

Score 0 if the individual gives an answer which is irrelevant or too vague (e.g. *"to see me"*).

2. Read the following part of the information sheet: *"Louise will arrange a time to meet that is best for you. This can either be at your home or at the learning disability team base. Louise will only ask you to meet up once".*

   Ask the potential participant: ***"How many times will I want to meet to talk?"***

   Score 2 for a clear and accurate answer such as *"once"*

   Score 1 if the individual gives and answer similar to but less clear than the above response

   Score 0 if the individual gives an answer which is irrelevant or too vague

3. Ask the participant ***"Are you happy for me to interview you?"***

   Answers **YES** or **NO**

   For consent to be given the participant needs to answer Yes to question 3

4. Read the following part of the information sheet: *"if you do not want to take part, just say no. If you say yes, but then change your mind, that is OK too"*

   Ask the potential participant: ***"what will you do if you change your mind?"***

   Score 2 for a clear and accurate answer such as *"tell you I don't want to do it anymore"*

   Score 1 if the individual gives an answer similar to but less clear than the above response

   Score 0 if the individual gives an answer which is irrelevant or too vague.

Overall scoring

		2	1	0
Question 1	*Why do I want to meet you and ask you some questions?*			
Question 2	*How many times will I want to meet to talk?*			
Question 3	*Are you happy for me to interview you?*	■		
Question 4	*What will you do if you change your mind?*			

If the potential participant scores 0 on any of the questions under items 1, 2, or 4, then they are assessed as not having capacity to consent in this specific context.

If the potential participant scores 2 on every question under items 1, 2, and 4 and answer *"yes"* to question 3, then they are assessed as having capacity to consent and are indicating their wish to participate.

If the potential participant scores 2 on every question under items 1, 2, and 4 and answers *"no"* to question 3, then they are assessed as having the capacity to consent and are indicating their refusal to participate.

If an individual scores 1 on **all** questions it would indicate that their responses are not very clear and that perhaps they are not adequately understanding the information. In this situation, you will need to discuss the individual's potential involvement with their carer or a member of staff who knows them well. Use your judgement to decide whether the individual has provided a sufficiently coherent understanding of the questions in the context of their level of intellectual disability, memory ability, and potential for suggestibility and acquiescence.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese, 1998.

Arscott, K., Dagnan, D., & Kroese, B. S. (1998). Consent to Psychological Research by People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities, 11*(1), 77-83.

Consent form

Service user experiences of DBT in an Adult Community Learning Disability Team

Please initial

1. I have been given information about the study (Participant information sheet 1 and 2).

2. I have been able to ask questions if I wanted, which have been answered.

3. I know that I can say no at any time.

4. Things that I say during the interview can be written in published reports without my name.

5. I agree to take part and complete an interview.

6. It is OK for my interview to be recorded.

7. I understand that if I say something to Louise which makes her worried about me or somebody else, she would need to tell somebody.

8. When the research has finished I would like Louise to write to me to tell me what she finds out.

Participant: Researcher:

Name: …………………………………………………   Name: ……………………………………………………….

Signed: ………………………………………………   Signed: ……………………………………………………...

Date: ……………………………………………….   Date: …………………………………………………………

Appendix 12: Sample participant verbal consent form

<u>Verbal Consent form</u>

Service user experiences of DBT in an Adult Community Learning Disability
Team

Please initial appropriate box

	YES	NO
1. I confirm that the participant has read or heard the information about the study (Participant information sheet 1 and 2).	☐	☐
2. The participant has confirmed that they have had the opportunity to ask any questions about the study, and such questions have been answered.	☐	☐
3. The participant has been informed that participation is their own choice and they can withdraw at any time without reason.	☐	☐
4. The participant has agreed for quotes from their transcript being used anonymously in future reports or publications.	☐	☐
5. The participant has agreed to take part in the study and complete an interview.	☐	☐
6. The participant has agreed to their interview being recorded.	☐	☐
7. The participant understands that the researcher may break confidentiality if they believe that the participant or another individual is at risk/in danger.	☐	☐
8. The participant has indicated that they wish to receive a summary of the results.	☐	☐

Name of researcher …………………………………………………………………………………

Signed: ……………………………………………………………………………………………….

Date: ………………………………………………………………………………………………….

Appendix 13: Semi-structured interview schedule

<u>**Semi-structured interview schedule**</u>

Prior to the commencement of the interview, participants will have previously received information sheet 1 and 2 explaining the purpose of the research. Participants will have also previously met with the researcher, where they will have discussed the research and participation in detail, and they will have had the opportunity to ask questions. Participants will all have been assessed and considered to have capacity to provide informed consent to participate by the researcher, prior to the arrangement of the interview. If participants were happy to participate, they will have provided either written or verbal consent prior to arranging the interview.

The following interview schedule will be used as a topic guide, but will remain flexible in nature. The researcher will be responsive to the participants' comments/insights and consequently may adapt and modify the ordering of the questions. In accordance with IPA techniques, the researcher will question further and follow up novel insights or reflections.

P indicates possible prompt questions

The researcher will introduce them self and the purpose of the study would be reiterated and the focus of the interview introduced such as:

> *"Hello, I'm Louise – I'm from Bangor University and I'm doing some research. My research is looking at what you think about DBT.*
>
> *You've been chosen to take part because you are taking part in, or have taken part in DBT. I would like to find out about what you think about DBT.*
>
> *[Produce consent form] I can see that you have already signed the consent form/I have signed that you understood what was going to happen and that you agreed to take part. I'll just remind you of a few things.*
>
> *During the interview I will ask you some questions about what you know about DBT, what you think is good and bad, and what, if anything, has helped you. I will record the interview using this recorder [produce Dictaphone]. It will only record our voices, not our faces.*
>
> *The interview will take around 1 hour, you can have a break if you would like to, or if you want to you can stop at any time. You can choose to stop the interview completely, or you can choose to stop and carry on another time, just let me know. If you choose*

to stop and not carry on that's ok, and all the information you have already given me will be destroyed.

If there are any questions that you don't want to answer, that is ok you can just tell me that you don't want to answer that question. If there are any questions that you aren't sure what they mean, please tell me and I will try to ask the question in another way [simplify without being seen to place opinion/influence the participant].

All of your information is confidential. If I use your information in my report, it won't have your name on it and people won't know that it was you. I won't tell anybody that you tell me, but if you tell me something that makes me worried about you or somebody else, then I might need to talk to other people about it, to make sure that you and other people are safe.

Do you have any questions?

Is it OK for us to start now?"

Demographic information/Engagement into DBT

1. **"Can you start off by telling me a little bit about you?"**
   P: how are you today, age, living arrangements, employment/work placements, education, family, hobbies, health.

2. **"Why did you start DBT?"**
   P: Why do you think DBT was suggested for you? How did you feel about DBT when you first talked about it? How did you feel before you started? What was it like when you first started? What were your expectations of DBT?

3. **"What is DBT?"**
   P: What is it for? Who is it for? What does it help people with? What do people have to do in DBT?

Skills Group

4. **"Can you tell me about the skills group?" [remind participant of where there group was and who the group leaders were if necessary]**

P: What is the skills group for? What happens in the skills group? What is it like? How do/did you feel attending the group? What is it like talking together/discussing your experiences in the group? What is it like being part of a group?

5. ***"Can you tell me what you have learnt in the skills group?"***

P: What is emotion regulation/distress tolerance/getting on with others/mindfulness about? What's it like learning the skills? Are there any topics/skills that you have found most useful?

Individual therapy sessions

6. ***"Can you tell me what your individual therapy sessions have been like? / About when it is just you and [therapist name]?"***

P: What happens? What are they for? How often do/did you see [therapist name]? How do you find [therapist name]?

Helpful and unhelpful components

7. ***"Can you tell me how DBT has helped you?"***

P: Is anything really helpful about the group? About your individual sessions?

8. ***"Can you tell me what has been unhelpful about DBT?"***

P: Is anything really not helpful about the group? About you individual sessions?

Supporting and maximising learning

9. ***"What helped you to learn the DBT skills?"***

P: Did you have homework tasks? Did you do them? Did they help? Did yu have any support from staff/family/PA? If yes, did it help? Did you get enough support?

10. ***"Are you able to use the DBT skills in your daily life?"***

P: How? Where? When? What helped? What didn't help?

Overall views and comments

11. ***"Has DBT changed your life in any way?"***

P: Quality of life? Relationships with others? Mental health?

12. ***"What things have you valued/found most important about DBT?"***

        P: What advice would you give to somebody else who was starting DBT?

13. ***"What are the worst things about DBT?"***

<u>General prompts</u>

Can you tell me some more about that/X?   What do you mean by X? How did you feel? Why? How?

Red – descriptive comments
Blue – Conceptual comments
Green – Linguistic comments

I: fab, ok. You said it helps you with your depression and anxiety?

P: yeah

I: how does it help?

P: it makes my anxiety less and my depression a bit less, like I feel bit better. [pause] cos I learn different things every day when go to DBT so erm [pause] I erm, learn like how to cope with things better, like things that would of made me anxious or depressed before. Like [pause] if someone puts pressure on you you know what to do, so you can say what you want and just walk away really.

I: yeah, so you learn new things every time that you go there yeah

P: yeah

I: ok, so it helps with anxiety and depression. Who's it for, who is DBT for?

P: erm, it's for people with problems, and people who struggle to cope and people with a learning disability. [pause] it's in [place] is it?

I: I think so yeah

P: I know some of the staff work at [place] offices

I: I see so it's across [place] and [place] isn't it.

P: yeah I think so

I: ok so it helps with anxiety and depression and things and it's about learning how to cope with different things

P: yeah

I: what do you have to do in DBT?

P: erm [pause] well we have a cup of tea *laughs* before we start talking an that and we have a chit chat and we have a break, erm and then we do we mindfulness with chocolate, mindfulness with sweets

I: what do you do with the chocolate?

P: well we put the chocolate by our lips and erm [pause] just like the taste, the feeling of it, then you put the chocolate further in your mouth and you have to like concentrate on the taste and the feel and stuff, you don't just put it

---

Descriptive comments (green, left margin):

Reduced distress.

Increased coping

Coping not changing or avoiding.

Self day.

Increased assertiveness

Problem people

Social connections important.

Fun experience

Some understanding

Understand process but not concept

→ Some understanding Focus

Annotations (right margin):

⑤

Depression decrease

Behaviour can change → Improved coping with things. → cope easier with things

Doing things avoid thinking

→ lots of things to learn. Always changing

Improved mindful emotion can reduce distress

Anxiety & depression less.
Feel better
Learn different things evy time
Learn how to cope better
Things would of struggled with before.

Increased assertiveness / interpersonal effectiveness.

For people with problems. People with a LD. Who can't cope.

Problem inherent in people? LD causes the difficulties?

Improving of social through social connection

Mindfulness

Have a cup of tea.
Laughter → indicating awareness that that isn't the most important part of DBT – or shouldn't be but it is really important.

Social element → most important.

Having fun → fun – being quite important

Fun

Mindfulness process

→ understanding of process / What is

straight in your mouth and eat it you have to do it proper slow

I: oh right I see, so you do mindfulness with chocolate and sweets and things

P: yea, we play games well they're like games it's like yeah games and we do erm walking around the, like with all the group walking around and do slow motions with our feet, fast slow erm [pause] we have a walk outside the building where DBT. So like you have to join in the games and stuff like that, they're like learning games though but they're good fun.

I: so lots of doing things and getting involved

P: yeah it's good

I: ok that's good. So who first suggested DBT to you?

P: erm [pause] think it was erm, social services, I think it was social services but where I was living in [place] the staff referred me or something like that.

I: Ok, and do you know who you first had a chat with about joining DBT?

P: Alex. Alex and Heather

I: ok, and why did they think that it was a good idea for you to start DBT?

P: because they could see that I was not coping very well in some certain stuff, and they said they would like me to join DBT so I did.

I: how did you feel when they first suggested DBT to you?

P: I felt ok, an then I thought ummm I dunno, because I was a bit wary because there was different people going with their own problems so I was a bit nervous really, I wasn't sure about what it was going to be like.

I: yeah

P: but it's good to hear about other people's problems as well, because [pause] I sometimes I sit back and I think 'oh I was like that' and makes you realise that other people sometimes don't cope as well. Makes me realise that I was like that but a long long time ago and now I've changed everything around, stopped me anger an everything so.

I: yeah, so you were a bit wary at first because there was going to be new people there, but then you thought it was a good thing as you got to hear

Handwritten annotations (left column):
Interactive sessions
promote engagement
fun
Group participation

DBT for people struggling to cope

Anticipatory anxiety
Fear of unknown
Social anxiety
Lge group.

validating shared is good
Reassuring
atmosphere
Self dev
shared experiences - not alone
Normalising

Handwritten annotations (right, blue):
understands concrete instructions?
Play games Fun?
→ They aren't 'games' just for fun, but are activities that are fun, but are for learning.
Interactive Engaging Doing Active
Walk around.
Games
Interactive activity in everything/doing

Handwritten annotations (right, red/pink):
Joined DBT as wasn't coping.
By mixed emotions.
Felt OK - then nervous/wary
re: starting. Anticipatory anxiety.
Wasn't sure what it would be like?
Anxiety re: unknown.
Anxious re: other people.
Good to hear about other people's problems.
Reassuring. Validating.
Normalising shared experiences. - can relate to others.
Sense of connection.
Not alone

about other people's problems so you realised you weren't the only one, and you also realised how much change you've made

P: yeah yeah

I: so that's good. Can you remember the very first time you went to group?

P: [wow] er [pause]

I: what was it like when you first went?

P: it was, it made it feel nervous a bit, but I knew a few people there like [name] and my friends an that. But, I felt really, good in myself, because everyone else had problems too, and I, there must be a reason why I wanted to go to DBT is to change things an that.

I: yeah, ok, so you were a bit nervous but you felt ok because you knew some people there

P: yeah

I: and you knew it was going to help you change some of the things you wanted to work on

P: yeah

I: that's good. [pause] erm, what did you think DBT was going to be like before you started?

P: [pause] boring. For the first time.

I: why did you think it was going to be boring?

P: because [pause] the first time it was like I don't know what it's all about, is it going to be boring? Like them just going on about stuff. An then, [eventually] I got in to it, and when we have cup of teas yeah it's good because we all get to chat together.

I: what's good?

P: yeah communicate with people

I: what people?

Left margin codes:
- not alone
- Proud of progress
- Initially anxiety provoking
- accepted?
- Normalising progress
- Expectations low
- Fears about being ridiculed?
- Socialising
- Building rapports
- Social connectedness
- belonging

Right margin annotations:
- Fits in / not out
- Not alone
- Proud. Progress. self dev.
- long time ago? Struggles to remember?
- nervous @ beginning
- Normalising. Peer support.
- Not alone
- managed in group
- social connection
- Tedious? A chore? D is ironic? meaning?
- Expected it to be boring
- no faith? (good)
- don't know what it was about
- unknown. unpredictable. Unfamiliar.
- cups of tea. chat together
- social element hugely important. connected.
- sense of belonging
- feel awards / ridiculed / inferior
- social rumour
- connectedness with others
- comfortable familiar
- tool to get / while

Inclusive Togetherness	P: the staff and the other service users, we all go together type thing.	All together. No power imbalance Togetherness. Inclusive. Belonging.
	I: yeah	
Social event Fun enjoyable	P: yeah we have a chat and have a laugh it's good.	Chat. Have a laugh. Social. making connections. Bonding. Fun. Laid back
	I: that's good isn't it. Tell me what it's like when you're in skills group. [pause] so you have a cup of tea and do some mindfulness, what else happens when you're there?	
	P: erm [pause] we just erm [pause] talk about oh, we go over the same things what we did last week, an that's so we get our minds on that, an they ask us what what did we do last week, an then once we've they've done it last weeks work, then we go onto the new work	Recap last week to focus / concentrate on that. Processing information - better consolidating new rules/ processes ...
	I: I see	
Repetition helps consolidate	P: yeah because then we can remember the stuff we did last time better before we do the new work.	Recap → remember what we did Repetition helps better consolidate.
	I: yeah, and what kind of stuff do you learn about?	To enhancing & understanding of emotions
Process of enhancing understanding of emotions	P: erm about erm, [pause] things about guilt, love, erm [pause] happy things that we have to like put names to the feelings like happy guilt and how, how it, what's the difference between the difference of guilt an things yeah	guilt, love, happy things. name emotions. Emotional literacy. ↓ identify differences.
	I: yeah	
Hard to learn	P: so it's hard sometimes but we go over it again every time, at the beginning before we do the new stuff, so they bring whatever we've done an then it brings our minds back to that, and then, which is helpful to go over it again	Helpful to go over material again. Repetition helps consolidate learning. Need to [learn] Lack of continuity from others
Repetition aids recall /consolidation	I: so it reminds you of it yeah	
Group dynamics	P: yeah, cos' there's people that have not really been turning up at group as well, so they need to know what we've been doing. We have to recap over the work again and again so they know what we've been doing.	People don't turn up. ↓ need to recap for them
	I: is there, what's that like when people don't turn up?	
Managing irritation	P: it's ok, but it is annoying sometimes because I think well, like, the last two weeks, not last week but the other week, there was [only] me and [name] there and [name] got his certificate and after that he didn't come back because he	Group dynamics annoying when people don't turn up. ↓ dysregulating Enhancing group dynamics

	Transcript	
Dysregulating experiences	finished his DBT [pause] an there was about three people there and we don't know why [name] didn't turn up, and it's annoying sometimes. But I do think the group works better in small	Repulsion — reinforce the irritation. Group better if small - less interruption? smaller group - less spread of money? more reliable? Easier to commit?
In-vivo exposure & practice	I: do you?	
Smaller group better	P: mmm, because there's certain people won't turn up	
	I: why do you think it's better when it's smaller?	
	P: because we're either starting late or people aren't coming on time which is annoying [pause] because really it starts at [time] and we have a break at [time] and we finish at [time] but sometimes we don't start until [time] and then it's rushed.	Repetition - reinforce irritation? Annoyance because it's rushed, smaller group avoids disappointment?
Rushed not good / helpful	I: I see, so you have to wait to see if people are going to turn up and that gets annoying	
	P: yeah [pause] there is certain people that turn up but sometimes not others	
	I: yeah. [pause] ok, how do you feel now when you go to group?	Group = comfortable. Safe place
Empowering experience	P: good [pause] I feel more confident and I feel like my whole, I feel relaxed	Feel more confident - relaxed. Group is empowering?
	I: yeah	
	P: yeah	
	I: why do you think you feel relaxed?	
	P: just talking about the beach, close your eyes an think about you're on the beach an, we did one last week and I was so cold *laughs* [pause] I was,	Exercises are relaxing?
	I: you were cold?	
	P: yeah,	
	I: why?	
	P: I don't know, it's, you know when you're cold an you wanna, and it's you're on the edge and you're cold at the edge, and then I come back an I feel better	
	I: right, ok	
	P: so yeah [pause]	

I: ok, so what's it like in group when you have to talk in the group?

P: [pause] I don't know what they other persons will say, do, you know, should I say that when there's loads of people around do you know what I mean, like it's a bit wary about what you should say an that

I: yeah, so you get a bit wary about what you should and shouldn't say in group

P: well yeah

I: that's kind of ok isn't it, I'm sure lots of people have those thoughts

P: but normally people if they've got issues, they talk after the group

I: right ok

P: cos' I've got a nurse that goes there an I can talk to them after the group and that

I: right

P: so some things I share in the group and some things I share to my community nurse. The sometimes like, the other people in group say, will help or say what they think as well. But sometimes I just only share to my nurse and she helps me.

I: I see, that sounds sensible. [pause] what's it like when other people share their problems?

P: it's quite difficult, because I feel sorry for the people then. [pause] this girl told me her problem last week an I said well I don't have that problem, an I felt really bad for her.

I: ah, that's not nice is it

P: no, it makes me feel sad for her. But it's good to share our problems sometimes because then sometimes we can help each other.

I: yeah, so you get some support and advice which can be helpful

P: yeah yeah

I: ok. [pause] what's it like being part of a group?

P: first thing, I've never liked groups I've never liked being in a big group or, I

Handwritten annotations (top margin): Process learning about social rules / keeping self safe

Right-hand handwritten notes:
- Don't know what others will say.
- Wary about what to say
- Nervous about what should share? Learning what's appropriate to share? keeping self safe. Unsure about sharing. Cautious about sharing
- got issues talk after the group
- awareness of support mechanisms → keep private issues out of group
- Personal info share privately
- Limits in sharing
- safe space
- Selective about what to share. Where others help. Peer support. seeking help. others help me - professionals & peers
- pressure to help offer advice?
- Difficult to hear others probs.
- Elicits difficult feelings when hearing others problems. managing difficult feelings in group.
- possible social discomfort. hard when can't relate?
- help each other. Peer support. Building support networks. connecting
- seek support
- Never liked groups.

Left-hand handwritten notes:
- Hard to share in group
- Limits to sharing. keeping self safe
- Social anxiety re group
- Individual needs. safe space to share
- Share personal info privately
- Support available
- Limits to sharing in group
- Peer support.
- others helping me
- Elicits difficult emotions hearing others' problems
- in vivo practise managing emotion

187

	I: why did you think it was gonna be strange?	Hot classes.
Strange. Unfamiliar and new concept/environment	P: I don't know, there's a lot of [pause] I don't know why, it just was strange to me cos I've never done that before [pause] I've done my time in DBT it's time for me to move on	Strange. Never done that before. New. Unfamiliar.
Timing and descending	I: is it	completed DBT. Learned all I'm going to learn?
	P: yeah it's time for me to move on and do other things	Been doing long enough? Going doing? constrained? destabilised?
anxiety re: starting	I: yeah. What was it like in the first group you went to?	Hard to rely on reflection? Numbers an overwhelming?
	P: nerve wracking.	nerve wracking
	I: was it	repeated exposure and practice reduces anxiety?
	P: yep	
	I: what about the second time?	
anxiety reduced over time	P: it was a bit nerve wracking still but it got easier and easier and easier	got easier. Anxiety reduces over time.
	I: ok, so it was really nerve wracking the first time but each time got easier	normal/familiar? Became familiar
	P: yeah	
	I: what do you think made it get easier as you went on?	
Familiarity/predictability reduced anxiety	P: I was quite focused, and got to know what was going to happen each time. Got to know the people too.	got to know what was going to happen. Became more familiar. Felt safe - gained trust in people?
	I: so being focused an	
	P: yeah wise mind	Wise mind. DBT concept.
Wise mind: thinking the 'right' way / Lack of understanding	I: what's wise mind?	Properly "right-way?" Some understanding? Not full. Particular 'right' way of thinking.
	P: where you're thinking properly	
	I: where you're thinking properly	

188

P: yeah

I: what does properly mean

P: it means that you thinking/sensibly] and you're [pause] an you talk respectfully and be respectful of one another and that's true isn't it?

I: yeah. [pause] ok, tell me a bit about the skills group, what's the group like?

P: [pause] it helps people to learn the skills that they need to help with their strategies if they've got an issue or [pause] that is what it's about, learning from your mistakes or your problems or get some help

I: yeah

P: you know

I: ok. [pause] and what happens in the group?

P: [pause] we have a massive conversation about things, that are important in our lifes

I: yeah, what kind of things might you talk about?

P: [pause] the rules in group, not to swear not to be rude not to be disrespectful, be kind to one another

I: mhm

P: be helpful

I: yeah, is it important to have those rules?

P: it is, cos if you didn't have those rules then, it would be breaking the rules anyway, might not work as good.

I: mhm

P: not doing the right thing. [pause] quite sad.

I: what's sad?

Margin annotations (top):

Logical/rational thinking
pleasure

together as a team ← from
some understanding. Not full.

consider past experiences, difficult situations

Thinking sensibly.

Say things in a helpful way? Not angry. Express self helpfully. Respectful

Learn skills.

need – requirement. Necessary. Can't manage without them in ... communicates importance.

Help with issues. Difficult situations

Learning from mistakes/problems.

Get some help – seek support.

Massive – enormity. Overwhelming? Lots of discussion.

Discuss important thing to them. 'our' → personalised. Things valued to them. Important? Clearly? Safety? special. meaningful?

Group rules.

Rules – without them group wouldn't work as well. Rules contain group. Rules help functioning. Highlights importance of rules. Necessity or wouldn't work.

Margin annotations (side/bottom):

consider options logically/rationally. positive understanding

Learning essential skills

Considering past experiences about situations to aid learning

intense/more discussions about valuable and important things

Valuable, person-centred discussion

(again)

Four respectful environment

Rules create safety

Rules contain the group

Appendix 15: Summary of superordinate and subordinate themes for each participant

	The impact of ID on therapy		Adapting therapy		The process of group learning			Personal Growth		
	Limited comprehension	DBT with a big 'B'	Adaptations to delivery	Carer involvement	Social connectedness	A platform of exposure	Individual sessions	Enriched sense of self	Reduced distress	Increased resilience
Rachel	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Tom	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
William	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Becky	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Alfie	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Natalie	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Appendix 16: Supplementary information 1 meta-analysis – full list of search strategies

Web of Science

1. TS=(Mindfulness OR Acceptance OR reflective practice) AND TS=(intellectual disabilit* OR learning disabilt* OR developmental disorder)

2. TS=(mindfulness OR acceptance and commitment therapy OR acceptance OR values OR reflective practice) AND TS=(parent* OR caregiver*) AND TS=(intellectual disabilit* OR learning disabilit* OR developmental disabilit)

3. TS=(mindfulness OR acceptance and commitment therapy) AND TS=(staff OR care* OR professional*) AND TS=(learning disabilit* OR intellectual disabilit*)

4. TS=(mindfulness OR acceptance OR psychological resilience) AND TS=(support staff OR caregiver OR parent OR professional) AND TS=(intellectual disabilit* OR learning disabilit* OR developmental dis*)

ProQuest

1. TI(intellectual disabilit* OR learning disabilit*) AND TI(staff OR caregiver* OR parent* OR professional) AND TI(mindfulness OR acceptance commitment therapy OR acceptance commitment training)

2. AB(intellectual disabilit* OR learning disabilit*) AND AB(staff OR caregiver* OR parent* OR professional) AND AB(mindfulness OR acceptance commitment therapy OR acceptance commitment training)

3. FT(mindfulness OR acceptance and commitment therapy OR acceptance) AND FT(intellectual disabilit* OR learning disabilit* OR developmental disorder)

Appendix 17: Supplementary information 2 meta-analysis – R script for all analyses

R code for meta-analyses

#Parent analysis

#Install packages

install.packages("metafor")

library(metafor)

input data for included studies, treatment groups and control groups (where appropriate)

datT <- data.frame(

m_pre   = c(124.2, 51.67, 12.74, 42.18, 11.81, 16.65, 35.17, 25.61),

m_post = c(98.5, 48.0, 10.53, 40.28, 7.50, 11.21, 31.72, 21.46),

sd_pre = c(8.7, 7.12, 4.27, 7.47, 4.46, 11.76, 11.43, 9.67),

sd_post = c(16.0, 7.8, 4.75, 8.62, 3.57, 7.07, 9.22, 9.77),

ni   = c(6, 6, 21, 91, 22, 26, 21, 52),

ri   = c(.70, .70, .70, .70, .70, .70, .70, .70))

datC <- data.frame(

m_pre   = c(109.4, 0.0, 0.0, 41.55, 0.0, 14.15, 38.28, 26.85),

m_post = c(108.9, 0.0, 0.0, 40.43, 0.0, 15.15, 37.61, 26.31),

sd_pre = c(15.8, 0.0, 0.0, 9.19, 0.0, 8.73, 11.43, 10.96),

sd_post = c(16.4, 0.0, 0.0, 8.90, 0.0, 6.59, 9.22, 9.95),

ni   = c(9, 0, 0, 89, 0, 20, 25, 52),

ri   = c(.70, .70, .70, .70, .70, .70, .70, .70))

Compute effect sizes for both groups

datT <- escalc(measure="SMCR", m1i=m_post, m2i=m_pre, sd1i=sd_pre, ni=ni, ri=ri, data=datT)

datC <- escalc(measure="SMCR", m1i=m_post, m2i=m_pre, sd1i=sd_pre, ni=ni, ri=ri, data=datC)

Compute the difference between effect sizes in the two groups and pool their variance. These are the effects the final meta-analysis will be based upon.

dat <- data.frame(yi = datT$yi - datC$yi, vi = datT$vi + datC$vi)

dat$Studies <- c('Ferraioli & Harris 2013', 'Hwang et al. 2015', 'Jones et al. 2017', 'Lo et al. 2017', 'Lunsky et al. 2015', 'Lunsky et al. 2017', 'Neece, 2014', 'Rayan & Ahmad 2017')

Add effect sizes from uncontrolled studies

dat$yi[is.na(dat$yi)] <- datT$yi[is.na(dat$yi)]

dat$vi[is.na(dat$vi)] <- datT$vi[is.na(dat$vi)]

#Fit model and make plots

rma(yi, vi, data=dat, method="REML", digits=2, slab = Studies) -> Model

forest(Model)

funnel(Model)

#Exclude outlier

dat[dat$Studies!='Ferraioli & Harris 2013',] -? dat1

rma(yi, vi, data=dat1, method="REML", digits=2, slab = Studies) -> Model1

###################

Analysis of professional carers

###################

datTProf <- data.frame(

m_pre   = c(16.78, 63.21, 66.5, 63.18, 34.16, 29.88),

m_post = c(15.44, 62.31, 66.13, 60.29, 21.81, 22.00),

sd_pre = c(13.32, 11.81, 18.62, 23.5, 2.96, 3.85),

sd_post = c(10.53, 14.78, 17.71, 19.16, 3.29, 4.02),

ni   = c(18, 37, 53, 34, 37, 33),

ri   = c(.70, .70, .70, .70, .70, .70))

```
datCProf <- data.frame(

m_pre   = c(17.81, 59.52, 66.37, 0.0, 35.13, 0.0),

m_post  = c(17.50, 59.23, 66.34, 0.0, 31.97, 0.0),

sd_pre  = c(11.03, 16.38, 19.32, 0.0, 2.33, 0.0),

sd_post = c(11.42, 16.31, 18.88, 0.0, 3.98, 0.0),

ni      = c(16, 21, 45, 0, 38, 0),

ri      = c(.70, .70, .70, .70, .70, .70))


datTProf <- escalc(measure="SMCR", m1i=m_post, m2i=m_pre, sd1i=sd_pre, ni=ni, ri=ri,
data=datTProf)

datCProf <- escalc(measure="SMCR", m1i=m_post, m2i=m_pre, sd1i=sd_pre, ni=ni, ri=ri,
data=datCProf)


datProf <- data.frame(yi = datTProf$yi - datCProf$yi, vi = datTProf$vi + datCProf$vi)

datProf$Studies <- c('Bethay et al. 2013', 'Ingham et al. 2013', 'McConachie et al. 2014',
'Noone & Hastings 2010', 'Singh et al. 2016a', 'Sing et al. 2016b')


datProf$yi[is.na(datProf$yi)] <- datTProf$yi[is.na(datProf$yi)]

datProf$vi[is.na(datProf$vi)] <- datTProf$vi[is.na(datProf$vi)]


dat

rma(yi, vi, data=datProf, method="REML", digits=2, slab = Studies) -> ModelProf

forest(ModelProf)

funnel(ModelProf)
```

<div align="center">**Thesis Word Counts**</div>

Thesis Abstract: 255

Chapter 1 – Meta-analysis and Systematic Literature Review:

Main text: 5, 900 words (excluding figures, tables and references)

Reference list, tables and figures: 4,441

Chapter 2 – Empirical paper:

Main text: 7,207 (excluding figures, tables and references)

Reference list, tables and figures: 3,148

Chapter 3 – Contributions to Theory and Clinical Practice:

Main text (excluding tables, figures and references): 4,280

References: 1,695

Total Word Count: 17,387 (excluding tables, figures and references)

Appendices Word Count: 16, 889 words (including appendices, tables, figures and reference lists, excluding ethics appendices)

Total Thesis Word Count: 35, 247 (including acknowledgements, table of contents, thesis abstract, figures, tables and reference lists)