VOLUME ONE: RESEARCH COMPONENT

OUTCOMES AND EXPERIENCES OF DIALECTICAL BEHAVIOUR THERAPY FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

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Thesis Overview

This thesis contains two volumes submitted as a requirement for the Doctorate in Clinical Psychology at the University of Birmingham. All identifying information has been anonymised to maintain confidentiality.

Volume one contains three research chapters. The first chapter presents a systematic review of the literature examining the outcomes of Dialectical Behaviour Therapy (DBT) for individuals with Intellectual Disabilities (ID). The second chapter is an empirical research study, exploring the experiences of DBT in a community setting for individuals with ID. The third chapter presents a public dissemination document, which provides a brief overview of the systematic review and empirical paper. An accessible summary of the main findings from the empirical paper was also developed for the individuals who participated in the research.

Volume two contains five Clinical Practice Reports (CPR's). The first presents a Cognitive-Behavioural and Psychodynamic formulation of a 26-year-old female experiencing anxiety in social situations. The second presents a service evaluation exploring staff perceptions of the effectiveness of a Triage Assessment Pilot in an Intellectual Disability Service. The third presents a case study of a 71-year-old male experiencing longstanding anxiety and depression. The fourth presents a single-case experimental design used to evaluate the effectiveness of an Acceptance and Commitment Therapy intervention for a 41-year-old male experiencing distressing thoughts. The fifth presents an abstract from a case study presentation of a 13-year-

old female, experiencing anxiety and depression, in the context of a chronic health condition.

Dedication

I would like to dedicate this to my wonderful Mum and Dad.

It has been such a journey getting here and I would not have been able to do it without the unconditional support you have provided, alongside the resilience and determination which you have instilled in me.

I am not able to put into words how much you mean to me and how grateful I am to have you.

Acknowledgements

Firstly, I would like to thank all the individuals who took part in the research. I truly value how willing these individuals were to sit with me and tell their stories. It was a privilege to listen and be part of this, and I hope that I have been able to capture the richness of their stories.

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A special thanks goes to my family, including my Mum, Dad, sister, brother, Nanny and niece for the support they have shown me throughout training and particularly whilst I have been carrying out this research. I would like to thank them for being so understanding when I have had to invest so much of my time in completing this project.

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CHAPTER 1

LITERATURE REVIEW

THE OUTCOMES OF DIALECTICAL BEHAVIOUR THERAPY FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES: A SYSTEMATIC REVIEW OF THE LITERATURE

Abstract

Background: Dialectical Behaviour Therapy (DBT) is an evidence-based treatment for Borderline Personality Disorder (BPD) and it is being increasingly utilised with other difficulties and populations. The National Institute of Health and Clinical Excellence (2009) recommends that individuals with mild intellectual disabilities (ID) and BPD should be able to access the same services as the wider population who have BPD. The current body of literature regarding the use of DBT for people with ID is limited, however there is growing interest in this area.

Aims: The aim of this systematic review was to examine the outcomes of DBT for people with ID.

Method: Five electronic databases (PsychINFO, Web of Science, Medline, Embase, Cinahl) were systematically searched and following the application of inclusion and exclusion criteria, a total of 13 studies were included in the review. The quality of the studies was appraised using the QualSyst tool.

Results: Key outcomes following DBT included a reduction in risk behaviours (e.g. self-harm and aggression), a reduction in psychological distress and improvements in global functioning and wellbeing. Other key findings included the application and generalisation of DBT skills. Quality appraisal of the studies highlighted that they were poor quality.

Conclusions: There are promising outcomes following DBT for individuals with ID, however, due to the poor quality of the studies, we were unable to confidently conclude that DBT was responsible for any of the outcomes reported. Clinical implications and suggestions for future research, including the need to conduct higher quality research, are considered.

Introduction

Dialectical Behaviour Therapy

Dialectical Behaviour Therapy (DBT) was originally developed by Marsha Linehan as a treatment for chronically suicidal individuals and it has subsequently evolved into a treatment for Borderline Personality Disorder (BPD) (Panos et al., 2014). DBT assumes that individuals with BPD engage in self-destructive, impulsive behaviours because they are lacking essential emotional regulation, distress tolerance and interpersonal skills; additionally, it posits that personal and environmental factors *inhibit* the use of adaptive behavioural skills that the individuals may have, and *reinforce* maladaptive behaviours (Linehan 1993a; Dimeff & Linehan, 2001).

DBT is underpinned by a 'dialectics' philosophy, whereby two opposing truths or ideas are balanced and synthesised (Pederson, 2015). A fundamental dialectic in DBT is that of 'acceptance' and 'change'. Sessions therefore aim to promote acceptance and validation of an individual's experiences, whilst also encouraging cognitive and behavioural change (Lippold, 2016).

DBT has five 'treatment functions', these include: enhancing the individual's capabilities by increasing skilful behaviours, improving their motivation to change and engage in treatment, ensuring that skills are generalised to other settings, enhancing the therapist's motivation to provide effective treatment and finally, supporting the individual to restructure their environment, to ensure that progress can be maintained (Linehan, 2015).

To achieve these functions, DBT uses a multi-modal approach. This includes group skills training, individual therapy, telephone support and therapist consultation. The group skills programme is made up of 4 modules: emotional regulation, distress tolerance, interpersonal effectiveness and mindfulness (McNair, Woodrow & Hare, 2015). 'Standard' DBT typically has a duration of 1-year (Flynn et al., 2017).

Effectiveness of DBT

There is a strong evidence base for the use of DBT with BPD; most empirical support comes from studies involving women with BPD who display parasuicidal behaviours (Chapman, 2006). A number of Randomised Controlled Trials (RCTs) have consistently found positive outcomes, including fewer hospital admissions, less suicide attempts, reductions in the severity and frequency of self-injury, reduced anger, improved social functioning and better treatment retention (Linehan et al., 1991; Linehan et al., 2006; Verheul et al., 2003). A meta-analysis by Panos et al. (2014) concluded that DBT is an efficacious treatment for reducing suicidal and self-harming behaviours in individuals with BPD. The National Institute for Heath and Care Excellence (NICE, 2009) also recommends the use of DBT for women with BPD, who frequently self-injure.

However, DBT is increasingly being adapted and applied to other difficulties and populations effectively. For instance, positive outcomes have been observed for individuals with post-traumatic stress disorder (Bohus et al., 2013), eating disorders (Safer & Jo, 2010), bipolar disorder (Van Dijk, Jeffrey & Katz, 2013) attention deficit

hyperactivity disorder (ADHD) (Hirvikoski et al., 2011) and older adults with depression (Lynch et al., 2003).

Intellectual disabilities and mental health difficulties

The term 'intellectual disability' (ID) refers to individuals with impaired intelligence (i.e. reduced ability to understand new or complex information and learn or apply new skills) and impaired social/adaptive functioning (i.e. reduced ability to cope independently); the onset is before adulthood, with a lasting effect on development (World Health Organisation, 2018).

It is estimated that 40% of individuals with ID also experience additional mental health difficulties, which is significantly higher than the wider population (Mencap, 2018). They may be more likely to have personality disorder (PD), however providing a diagnosis is often difficult due to the lack of valid, reliable diagnostic instruments and the overlapping features of PD and ID; for instance, features associated with BPD, such as impulsivity, affective lability and self-injurious behaviours, also frequently occur in people with ID (Pridding & Procter, 2008; Alexander & Cooray, 2003).

Intellectual disabilities and psychological therapy

Despite the high prevalence of co-morbid mental health difficulties, individuals with ID have historically had limited access to psychological interventions (Whitehouse et al., 2006). The Department of Health (2009) highlights that individuals with ID should have the same access to psychological therapies as the general population. In recent

years there has been greater recognition of the importance of individuals with ID accessing appropriately adapted psychological therapy, and these individuals are increasingly receiving a range of psychological therapies (Irvine & Beail, 2016).

However, the evidence base relating to the effectiveness of psychological interventions for people with ID is limited, and there is a significant need to develop this research area (Bhaumik et al., 2011). In a review of the available literature, findings indicated that a range of therapies including Cognitive Behaviour Therapy, Systemic Family Therapy, Psychodynamic Psychotherapy and counselling, can be adapted for people with ID and show promising results (Brown et al., 2011). However, much of the research was methodologically weak, making it difficult to draw meaningful conclusions. Moreover, particular therapies including DBT were not included in the review due to a paucity of the literature.

Intellectual Disabilities and DBT

NICE (2009) recommends that individuals with mild ID and BPD, should be able to access the same services as the wider population who have BPD. Lew et al. (2006) suggests that the underlying philosophy of DBT is in line with the needs of people with ID, in that it is skills based, promotes acceptance rather than blame and encourages independence and empowerment.

Whilst there appears to be a clear rationale for providing DBT to individuals with ID, the current body of literature is limited; however, this research area does appear to be gathering momentum (Crossland, Hewitt & Walden, 2017). In a review of the

available literature, McNair, Woodrow and Hare (2017) concluded that DBT can be adapted for individuals with ID, however conclusions about efficacy or effectiveness could not confidently be made, due to the quality of the available literature.

Current review

At the time this review commenced, the author was not aware of the review conducted by McNair et al. (2017). However, the previous review by McNair et al. (2017) only considered quantitative studies (with the exception of one mixed-methods study); given the infancy of this research area, a systematic review of the literature which includes qualitative and quantitative studies is warranted.

This paper aims to review the available evidence in relation to the use of DBT for individuals with ID, with a particular focus on extracting and synthesising the qualitative and quantitative outcome data reported within the studies. It is hoped that this will provide greater insight into the impact of DBT for people with ID.

Method

Search strategy

A systematic search of the literature was conducted in August 2018 using the following electronic databases: PsychINFO, Web of Science, Medline, Embase and Cinahl. Search terms were developed based on the terms used in previous systematic reviews regarding DBT or people with ID. These terms were truncated and the ‘explode’ function was used where available, to maximise the results identified. Search terms were combined using “OR” and “AND” (see Table 1). Due to the paucity of the literature, no limiters were applied during the search.

Table 1. Search terms for electronic database searches

Intellectual Disability search terms		**Dialectical Behaviour Therapy search terms**
Learning Disab*		Dialectical Behav* Therap*
OR		OR
Intellect* Disab*		DBT
OR		
Development* Disab*	AND	
OR		
Mental* Retard*		
OR		
Learning Disabilities *(exploded)*		
OR		
Intellectual Development Disorder *(exploded)*		
OR		
Developmental Disabilities *(exploded)*		

Procedure

In order to aid transparency, and in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009), the different phases of the review are presented in Figure 1.

In total, 184 articles were identified from the search; 1 further article was found through reference list searching. Following removal of duplicates (n=50), the titles and abstracts of the remaining 135 articles were screened and 116 were subsequently excluded. The full texts of the remaining 19 papers were assessed for eligibility using the inclusion/criteria (see Table 2), which was developed using the PICOS model (Participants, Interventions, Comparators, Outcomes, Study Design) (Huang, Lin & Demner-Fushman, 2006). A total of 13 articles met the inclusion criteria and were therefore included in the current review.

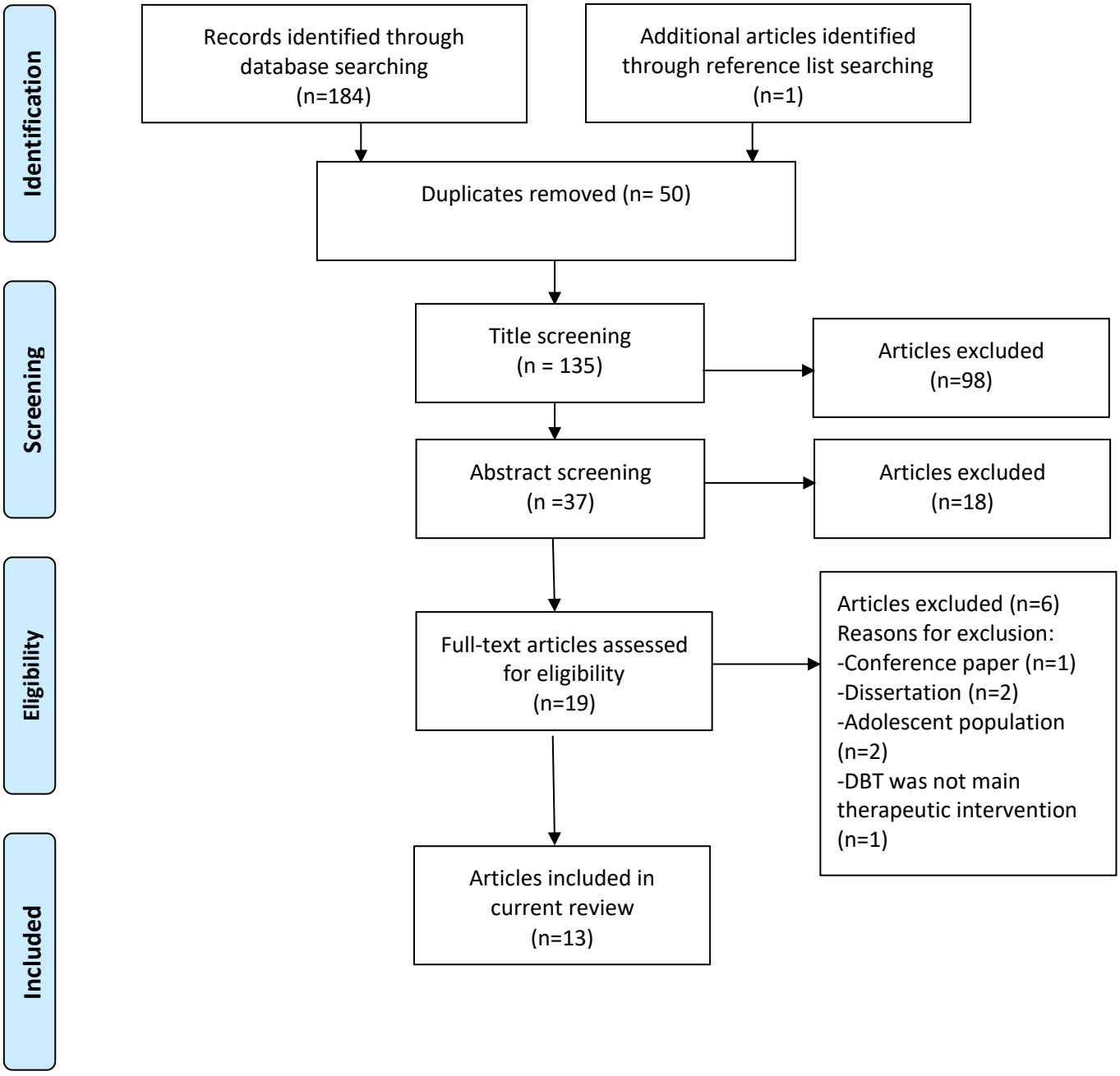


Figure 1. PRISMA flow chart of the systematic review process

Table 2. Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Has a clear focus on participants with intellectual disabilities	Excludes studies where participants with intellectual disabilities were not the research focus
Has a clear focus on participants who have received Dialectical Behavioural Therapy (e.g. the complete multi-modal DBT intervention or key components of the treatment, such as the DBT skills group)	Excludes studies where a DBT intervention was not the research focus
Includes participants with any presenting difficulty where DBT was used as the main therapeutic intervention	Participants are under 18 years of age
Includes participants who are over 18 years of age	Excludes studies which do not report quantitative/qualitative data relating to outcomes/change following a DBT intervention
Includes data relating to the outcomes or changes following DBT (including qualitative outcome data)	Excludes unpublished research papers
Published research papers (in peer reviewed journal)	
Any study design (including quantitative, qualitative and mixed-methods)	
Any clinical setting or country	

Data extraction

In accordance with guidance from the Cochrane Handbook of Systematic Reviews of Interventions (Higgins & Green, 2011), relevant data was extracted from the 13 studies identified; this included data regarding study designs, participant characteristics, settings, intervention details, outcome measurement and key findings.

Quality appraisal

The quality of the papers was assessed using the QualSyst tool (Kmet, Lee, & Cook, 2004); this tool was selected as it can be applied to a range of study designs and provides separate checklists for quantitative and qualitive studies. Moreover, it has also been utilised in similar ID research previously (Unwin et al., 2016). The tool defines 'quality' in terms of internal validity, or the extent to which the conduct, design and analyses minimise bias and errors.

For each of the papers, items on the quality checklist were either rated as 'yes' (score 2), 'partial' (score 1), 'no' (score 0) or 'not applicable' (deduct 2 from the total *possible* score). The total score is divided by the total *possible* score in order to calculate a 'summary score' (i.e. the quality score) (Appendix 1 & 2). However, authors provide no indication of what this numerical summary score means in terms of study quality. Buckman et al. (2018) developed a scoring system in relation to the QualSyst, and this was therefore utilised by the current review (see Table 3).

Table 3. Scoring system for QualSyst checklist

Summary score	Indication of study quality
0-0.25	Very low quality
0.26-0.50	Low quality
0.51-0.75	Moderate quality
0.76 or above	High quality

In order to reduce potential subjectivity when applying the appraisal tool, a selection of 4 papers were independently rated by a second reviewer. Agreement across papers was generally good and any discrepancies were resolved through discussion.

Results

General description

Table 4 provides a summary of the of the relevant data extracted from the thirteen studies. Of these thirteen papers, eight were quantitative papers (four case studies, three repeated measures designs, one multiple baseline design across participants), two used mixed-methods designs (repeated measures and Thematic Analysis) and three were qualitative papers (two used Interpretative Phenomenological Analysis (IPA) and one utilised a Case Orientated Approach).

Table 4. Summary tables of the reviewed papers

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Baillie & Slater (2014) To reflexively examine the challenges and lessons learnt from implementing a community based DBT service for adults with ID.	Case study (as defined by author)	N=19 (11 males, 8 females) Ages not specified. Mild to moderate ID. All had 'severe emotion regulation' difficulties, 3 met criteria for BPD, 9 displayed suicidal or para-suicidal behaviours, 5 engaged in risky behaviours, 13 displayed verbal or physical aggression and 4 had Autism Spectrum Disorder (ASD). Community based DBT service, in the UK.	DBT Skills group (weekly) Individual Therapy (weekly) Telephone Coaching (Monday-Friday, 9am-5pm) Team Consultation (fortnightly) Interventions for the clients support services, including carers group (weekly) Duration-1.5 years- 2.25 years	The Symptom Checklist-90-Revised (SCL-90-R) (Derogatis, 1994) The Health of the Nation Outcome Scale–Learning Disability version (HoNOS-LD) (Roy et al. 2002) The DBT Carers' Feedback Questionnaire (DBTCFQ) (Developed by service) Costs saved in relation to the accommodation participants were living in.	No outcome data was reported from the measures used. Authors noted that the clinical and statistic utility of the SCL-90-R was compromised due to the number of adaptions which needed to be made. They suggested that the HoNOS-LD may lack sensitivity to measure psychological change. Authors noted that initial results suggest that the DBTCFQ was sensitive to change, however, they were unable to carry out a statistical analysis due to insufficient client numbers. 8 out of the 19 participants were at risk of placement breakdown due to the challenges they presented. Of these, 6 were able to stay in their current accommodation following DBT. This outcome was associated with significant financial costs being saved and a better quality of life for the clients. Authors also anecdotally noted improvements in emotional regulation and distress tolerance.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
McNair, Woodrow & Hare (2015) To present two case studies of individuals with intellectual disabilities who received adapted DBT and use repertory grid techniques to measure psychological change following treatment.	Case study	N= 2 (females) 'Sarah' aged 22 with ID (level of ID not specified). 'Laura' aged 18 with 'suspected' ID. Both had difficulties with parasuicidal behaviours and self-injury. Specialist community psychology service, in the UK.	DBT Skills group Individual therapy Duration- not specified	Repertory grid technique (pre-treatment and post-treatment)	'Sarah'- reduction in distance between 'self' and 'ideal self' on repertory grids, indicating increased self-esteem. There were some changes in her construing, suggesting that she viewed herself in a more positive light following DBT. She was able to resolve implicative dilemmas. She reported a reduction in self harm and improvement in using strategies to help her cope when distressed. 'Laura'- increase in distance between 'self' and 'ideal self', indicating continued low self-esteem. Little change in construing had occurred. She identified implicative dilemmas which had not been there at the start of DBT. There were continued high levels of self-harm.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Ashworth, Mooney & Tully (2017) To evaluate the effectiveness of an adapted DBT programme ('I Can Feel Good') in relation to adaptive emotion management, for a male with mild ID and BPD in a medium secure forensic setting.	Case study	'Mr C' N=1 (male). Age not specified. Mild ID (IQ= 69 according to most recent test). Diagnosis of BPD. Presented with behavioural difficulties including aggression and self-harm. Prior charges/ convictions for offending behaviours. Medium secure forensic setting in the UK.	Adapted DBT programme- 'I Can Feel Good' (Ingamells & Morrissey, 2014) Group (weekly, 2 hours) The first 3 modules were completed in group format and the last module (9 sessions) was completed individually. Individual sessions DBT Consultation Duration- 47 weeks	Emotional Problems Scale-Behaviour Report Scale (EPS-BRS) (Prout & Strohmer, 1991) Cognitive and Affective Mindfulness Scale–Revised (CAMS-R) (Feldman et al., 2007) Emotional Control Questionnaire (ECQ) (Roger & Najarian, 1989). Coping Response Inventory (CRI) (Moos, 1993). Chart of Interpersonal Reactions in Closed Living Environments (CIRCLE) (Blackburn & Renwick, 1996).	There was little change on the EPS-BRS. This scale indicated that risk was maintained. Mindfulness skills improved according to self-report data, but this was not observed by staff**.** ECQ indicated little impact on self-reported emotional control strategies. CRI suggested on the one hand that he was less likely to use maladaptive coping strategies, whilst indicating that he was also less likely to use more positive coping strategies. Changes on CIRCLE indicated a shift towards a more negative interpersonal style.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Florez & Bethay (2017) To present the case of an individual with mild ID, who experienced emotional dysregulation, challenging behaviours and generalized anxiety, and document the results of the adapted DBT treatment received.	Case study	'Gaby' N= 1 (female). 28 years old. Mild ID. Diagnosis of Generalised Anxiety Disorder (GAD) and Intermittent Explosive Disorder (IED). Presented with behaviours that challenge (e.g. aggression, self-harm, being 'un-cooperative' and elopement) and emotional dysregulation. Residential intermediate care facility for individuals with ID, in the USA.	DBT Group skills (weekly, 45 minutes) This was delivered on an individual basis. Individual therapy (weekly,1 hour) No telephone coaching but she was able to call other professionals involved. Duration- 1 year	Frequency of challenging behaviour Staff qualitative reports Therapist's behavioural observations	Decrease in challenging behaviours, including periods of zero frequency. On occasions when challenging behaviour was apparent, the frequency and intensity was lower compared to baseline. Staff qualitative reports- improvement of mood, use of better strategies to manage problems, better regulation of emotions, appropriately communicating distress. Therapist observations- improvement in emotional awareness, problem-solving skills, and confidence when dealing with crises. 'Gaby' echoed these improvements.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Sakdalan, Shaw & Collier (2010) To evaluate the effectiveness of a DBT skills group, which had been adapted for offenders with ID.	Repeated measures design	N= 9 (7 males and 2 females) with a formal ID diagnosis. Individuals displayed behaviours which challenge and all had prior charges/ convictions for offending behaviours. Further demographics were provided for the 6 treatment completers (5 males, 1 female). Ages ranged from 23-29 (mean= 26.18) and all had a mild or moderate ID (mean IQ= 57.17) ID Offender Liaison Service in New Zealand.	DBT Skills group (weekly, 1.5 hours) DBT group supervision Structuring the environment Ongoing training to vocational and residential staff Duration-13 weeks	Short-term assessment of risk and treatability (START) (Webster et al. 2004) Health of the Nation Outcome Scales for people with learning disabilities (HONOS-LD) (Wing et al. 1996) The coping skills subdomain within the Vineland Adaptive Behaviour Scales–Second Edition (VABS-II) (Sparrow et al. 2005) Incident reports DBT assessment and feedback form (a 9-item questionnaire to assess learning from the course and to elicit feedback)	Results from the START measure showed significant improvements in both the risk domain ($p < 0.05$) and the strength domain ($p < 0.01$). Significant improvements were observed on the HoNOS-LD ($p < 0.05$) Improvements in coping skills on the VABS-II were noted, but these were not significant. Data from the incident forms were not provided Participants scored within the moderate to high range on the DBT assessment form, suggesting that they had learnt the principles of DBT. Feedback indicated that they had learnt a lot from the course enjoyed it.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Morrissey & Ingamells (2011) To describe the development of an adapted DBT programme for male offenders with mild ID in a high secure setting over a period of 6 years. This includes a rationale for the programme, how it has evolved, modifications made and challenges that remain.	Repeated measures design	N= 6 (males). Ages not specified. Average IQ for the service was 64, but average IQ for participants specifically was not given. All met diagnostic criteria for at least 1 PD (type of PD not specified) and had problems with emotional or behavioural regulation. All presented a high risk of harm to self and others. Waiting list control group (n=5) (no other information provided) High secure forensic ID service, in the UK.	DBT Group Skills (weekly) Individual Therapy (weekly) Telephone coaching was not provided but staff were available to support participants Team Consultation (every 4-6 weeks) Duration- 18 months	Global Severity of Distress Scale of the Brief Symptoms Inventory (BSI) (Derogatis 1993). Incident reports (e.g. self-harm and aggression)	Authors reported 'significant' reductions on the Global Severity of Distress Scale of the BSI (however no statistical analysis was provided). Incidents of aggressive behaviour were not significantly different; however, the baseline was low due to the high security setting. In the 12 months following treatment, participants were more likely to have moved to lower security settings compared to the control group (4 out of 6, compared to 1 out of 5). All 4 have remained in lower security conditions. Anecdotally, authors noted an increase in emotion regulation skills; they associated this change with reduced seriousness of self-injury and interpersonal aggression.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Brown, Brown & Dibiasio (2013) To examine whether individuals with intellectual and developmental disabilities (ID/D) who received an adapted DBT programme (DBT Skills System (DBT-SS)) showed reductions in behaviours that challenge.	Multiple baseline design across participants	N= 40 (35 males, 5 females) Ages ranged from 19 to 63 (mean= 30.8). 82% had an IQ below 70 (ID). All had a history of displaying challenging behaviours, including suicide attempts, self-injury, fire setting and aggression. 8 had a diagnosis of BPD. Participants had a range of co-morbid psychiatric disorders including anxiety and mood disorders and sexual disorders. Justice Resource Institute- Integrated Clinical Services (ICS), in the USA	Group Skills training (weekly, 1 hour) Individual therapy (weekly, 1 hour) Telephone coaching Team Consultation (weekly) Additional weekly 1-hour group for participants with histories of sexual offending behaviours Training and consultation to staff members involved in clients care Duration- mean 6.9 years	Incident reports of problematic behaviours were classified in the following way: -'Red Flags' (low level behaviours e.g. shouting, swearing). -'Dangerous situations' (medium level behaviours including an escalation beyond verbal outburst e.g. threats of violence, slamming doors) -'Lapses' (high level behaviours including violent or illegal actions e.g. self-harm, aggression)	There was a significant reduction in red flags ($p < .001$), dangerous situations ($p < .003$) and lapses ($p < .001$). (Data was from the first 4 years of treatment) Results suggest that most improvement occurred in the first year and these improvements were maintained in subsequent years, but the statistical significance was not as robust. The more severe behaviours appeared to improve more gradually over the 4 years compared to the less severe behaviours. Fewer clients were hospitalised or spent time in forensic settings during the first 2 years of treatment compared to the 2 years prior to treatment (2 out of 40 compared to 28 out of 40).

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Lew, Matta, Tripp-Tebo, & Watts (2006) To describe the adapted DBT programme provided to individuals with ID and provide data following its implementation.	Repeated measures design	N= 8 (females) Ages ranged from 25-61. 7 mild ID, 1 moderate ID. Average of 1.38 Axis 1 diagnoses (major depression and schizoaffective disorder were the most common) 5 had diagnosis of personality disorders (not specified). Described as 'multi-problem individuals' who were seen as a risk in the community and their clinical needs were not currently being met by services Specialist ID community service, in the USA.	DBT Group skills (Weekly, 2 hours, repeated 3 cycles of the 23 week programme) Individual therapy (Weekly 1 hour or 2x 30 minutes) Coaching in crisis (24-hour availability by pager and scheduled phone in times for some individuals) Consultation team (two teams which met weekly and monthly) Structuring the environment to support treatment Duration-69 weeks	Adapted version of the Youth Risk Behaviour Survey (RBS). (Centers for Disease Control and Prevention, 2001). 22 of the 87 items were considered to be relevant for people with ID.	Risk behaviours (as measured by risk indicators on RBS) appeared to get worse between baseline and the 6-month interval ('incidents of worsening'= 54%, 'incidents of no change'= 16% and 'incidents of improvements'= 30%). At the 12-month interval, risk indicators had improved by 60% compared to baseline, 22% stayed the same and 18% had worsened. This pattern of improvement in risk indictors was maintained at 18 months. There was a noteworthy decrease in the number of individuals self-harming from baseline to 18-months. Authors noted that this reflected a slow but gradual change.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Crossland, Hewitt & Walden (2017) To evaluate a community based DBT group for individuals with ID, using qualitative and quantitative data	Mixed methods (qualitative and repeated measures design)	N=4 (3 females, 1 male). Ages ranged from 24-48. All had mild ID. 2 had diagnosis of BPD. Other diagnoses included Obsessive Compulsive Disorder (OCD), ASD and, Depressive disorder. All had interpersonal difficulties or difficulties in emotional regulation. Community setting, in the UK.	DBT group (weekly) Duration-18 weeks	**Quantitative:** The Health of the Nation Outcome Scales—Learning Disabilities (HoNOS-LD) (Roy et al. 2002) The Psychological Therapies Outcome Scales—Intellectual Disabilities (PTOS-ID) (Beail, Vlissides, & Jackson, 2015). **Qualitative:** A semi structured interview was conducted with the clients and support staff following the intervention (interviews carried out separately). Questions related to what was helpful/ unhelpful and future changes/ adaptions to the group. Analysed using Thematic Analysis (Brain & Clarke, 2006).	**Quantitative:** Scores decreased on HoNOS, suggesting improvements in overall functioning There was an increase in scores between post-group and 4-month follow up for 2 participants, but all scores were lower overall at follow up compared to baseline. Scores on the PTOS-ID indicated that psychological distress decreased following the group and this continued to decrease for 3 people when measured at follow up. 1 participant had increased scores of psychological distress at follow up compared to baseline. Scores indicated that positive wellbeing increased for all participants following the group. This was maintained or improved further for 3 individuals but decreased to baseline for 1 person. **Qualitative:** 6 client themes emerged- 'Interpersonal Relationships', 'Group Boundaries', 'Making Theory-Practice Links',

					‘Remembering Our New Skills’, ‘Generalising Skills Outside The Group’ and ‘Suggestions For Improvements’. 5 Support staff themes emerged- ‘A Supportive Group’, ‘Respect For The Group and Its Members’, ‘Group Content and Organisation’, ‘Support Staff Attending Group Is Helpful’ and ‘Using Skills Outside The Session’ Key qualitative findings relating to outcomes- some participants reported effectively using DBT skills in their day to day lives, whilst others struggled with recalling or generalising skills. Some individuals reported developing interpersonal relationships within the group.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Hall, Craven, & Woodrow (2013) To evaluate a community based DBT programme for adults with ID	Mixed methods (qualitative and repeated measures design)	N=7 (quantitative) N= 5 (qualitative) Age and sex not given. All had intellectual disability (level not specified). No diagnoses provided. Difficulties with emotional regulation, managing crisis and interpersonal effectiveness. Community setting, in the UK.	DBT Skills group Individual therapy Consultation group Carers component as an alternative for the 24-hour telephone support Duration-not specified	**Quantitative:** Glasgow Depression Scale (GDS) (Cuthill, Espie & Cooper, 2003) Glasgow Anxiety Scale (GAS) (Mindham & Espie, 2003) Cognitive Affective Mindfulness Scale-Revised (CAMS-R) (Feldman et al., 2007). **Qualitative:** semi structured interviews were conducted about the group component of the programme. Analysed using Thematic Analysis (Braun & Clark, 2006).	**Quantitative:** Reductions in anxiety and depression symptoms were observed. GDS scores decreased from above clinical cut off to below at the end of the programme. Scores on GAS decreased, but still remained above the clinical cut off. Scores on CAMS-R increased, indicating improved mindfulness skills and attitudes of acceptance and non-judgement. Statistical analysis was not carried out due to sample size. **Qualitative:** Four themes emerged- -'Good things about the group' -'Bad things about the group', -'After the group' -'In the future'. Key qualitative findings relating to outcomes- participants felt more in control of their emotions and were able to manage difficult situations using less destructive means. They also reported a reduction in self harming and not being in trouble with the police as much. Participants also described

					developing their own personalised skills and continued use of skills after the group had finished.

Study and Aims	**Study design**	**Sample**	**Intervention**	**Measures**	**Key findings related to the outcomes of a DBT intervention**
Roscoe, Petalas Hastings & Thomas (2016) To explore the experiences and views of female inpatients with ID and PD who have received DBT	Qualitative	N=10 (females) Ages ranged from 19-57 (Mean= 44.90). All had mild ID (IQ ranging from 60-70). 9 had BPD (1 of which was also deaf). 1 had additional diagnosis ADHD. 1 had diagnosis of dependent PD. Inpatient setting (2 private mental health hospitals) in UK	DBT skills group Individual therapy Duration-participation in the programme ranged from 3–23 months across participants.	Semi-structured interviews were conducted. Participants were asked about: their views and experiences of DBT, their understanding and knowledge of DBT. Analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009).	Three themes were identified: -'Understanding DBT' -'DBT as helpful and beneficial' -'Engagement with the DBT process' Key findings relating to outcomes-data suggested that participants had been able to apply the skills they had learnt in DBT to manage difficult situations. They experienced better communication, negotiation and relationship skills. They reported better control over 'extreme' emotions and noticed changes in affect. Data also indicated that they had been able to reach personal understandings of the programme.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Thomson and Johnson (2017) To explore the experiences of females with ID within a secure forensic service, who received DBT	Qualitative	N=7 (females) Age range and other demographic details not provided. Authors noted that some of the women in the service have BPD and ID but did not specify details for the study participants. Presenting difficulties not reported. Secure forensic service (low to medium secure), in UK.	DBT Skills group Individual therapy Duration- 1-year duration	Semi-structured interviews were carried out. Questions related to: describing DBT, the tools/ processes involved in the therapy and any changes/ evaluation of the therapy. Analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). Service evaluation data around number of incidents	Three themes emerged: -'How you do DBT' -'What we think about DBT' -'Using DBT' Key findings relating to outcomes- data suggested that individuals had been able to implement a variety of the skills they had learnt and had made them personalised/ meaningful for themselves. They were able to utilise skills when responding to difficult situations and planned to continue using these skills following ending treatment. Inconsistent staff knowledge/support was noted as a barrier to implementing skills. Individuals reported feeling calmer. Participants were able to develop relationships within the group and noted improved relationships with ward staff (this was linked to a decrease in aggressive incidents). Participants reported feelings of hope for the future. Quantitative data for service evaluation demonstrated a reduction in incidents of self-harm and aggression.

Study and Aims	Study design	Sample	Intervention	Measures	Key findings related to the outcomes of a DBT intervention
Johnson & Thomson (2016) To explore the experiences of individuals with ID who received DBT and staff members experiences of implementing DBT in a forensic intellectual disability service	Qualitative	N= 14 (7 staff members and 7 service users). 7 service users were females. No other demographic detail was described. Presenting difficulties not reported NHS forensic ID setting, in the UK.	DBT Skills group Individual therapy Team consultation Duration- not specified	Data comes from interviews carried out in 2 previous qualitative studies: (1) staff interviews (from unpublished study) (2) client interviews (from Thomson & Johnson, (2017) outlined above) Case orientated approach (Baxter & Jack, 2008) was used to look at these two data sets, looking for commonalities across and within studies.	Three themes emerged: -'Trust' -'Intensity' -'Worthwhile' Key findings relating to outcomes- Staff noted that an individual was able to receive leave from the forensic service after 29 years of not being able to. Participants reported developing skills to manage difficult emotions and situations more effectively. They described developing trusting relationships with staff and clients. Findings suggested an improved sense of self-worth and that they were on a journey towards 'a life worth living'.

Quality appraisal for quantitative papers

Ten papers were reviewed using the quantitative QualSyst tool (see Table 5 & 6). As two papers used mixed-methods designs, they were reviewed using both the quantitative and qualitative checklists.

Quantitative studies scored between 0.31-0.62, indicating that they ranged from low-moderate quality. Research questions/objectives were often not clearly described; study designs were weak and largely inappropriate for the research aims. The absence of control groups meant that random allocation, controlling for confounding variables between groups and blinding of participants/investigators was not possible. Only one study referred to a 'waiting list' control group, but no further information was given. Sample sizes were small, the reporting of participant selection methods was limited, and description of important participant characteristics was often lacking; however, this was a relative strength for 3 studies (Florez & Bethay; Brown et al., 2013; Crossland et al., 2017). Many outcome measures were not well defined and did not appear to be robust to measurement bias. Analytic methods were largely not carried out due to small sample sizes and estimates of variance were rarely reported. The majority of studies did not report results in sufficient detail. Whilst most studies acknowledged methodological limitations, the conclusions made perhaps needed to be presented more tentatively, given the weaknesses highlighted.

A limitation of the QualSyst is that it does not consider the 'hierarchy of evidence'. This is important to acknowledge, as many of the papers were case studies or uncontrolled studies, and these types of designs are generally considered lower

quality evidence, whilst RCTs represent higher quality, ‘gold standard’ evidence (Barton, 2000; Burns, Rohrich & Chung, 2011). Additionally, it is important to note that many of the items on the QualSyst were ‘not applicable’ for the case study papers; this meant that case studies had a lower ‘total possible score’ compared to the other papers and subsequently received higher ‘summary scores’ and ‘quality ratings’ for the most part. Therefore, the quality of the case study papers particularly appears to be overinflated and should be held with caution.

Table 5. Quality checklist ratings for quantitative studies (case studies)

	Baillie & Slater (2014)	McNair et al. (2015)	Ashworth et al. (2017)	Florez & Bethay (2017)
1. Question/objective sufficiently described?	2	2	2	2
2. Study design evident and appropriate?	1	0	0	1
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?	N/A	N/A	N/A	N/A
4. Subject (and comparison group, if applicable) characteristics sufficiently described?	1	1	1	2
5. If interventional and random allocation was possible, was it described?	N/A	N/A	N/A	N/A
6. If interventional and blinding of investigators was possible, was it reported?	N/A	N/A	N/A	N/A
7. If interventional and blinding of subjects was possible, was it reported?	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?	1	2	2	1
9. Sample size appropriate?	0	0	0	0
10. Analytic methods described/justified and appropriate?	0	1	1	0
11. Some estimate of variance is reported for the main results?	N/A	N/A	N/A	N/A
12. Controlled for confounding?	N/A	N/A	N/A	N/A
13. Results reported in sufficient detail?	0	2	2	2
14. Conclusions supported by the results?	1	1	2	1
Total score/total possible score: Summary score: Quality rating:	6/16 (0.37) Low quality	9/16 (0.56) Moderate quality	10/16 (0.62) Moderate quality	9/16 (0.56) Moderate quality

Table 6. Quality checklist ratings for quantitative studies (group studies)

	Lew et al. (2006)	Sakdalan et al. (2010)	Morrissey & Ingamells (2011)	Brown et al. (2013)	Hall et al. (2013)	Crossland et al. (2017)
1. Question/objective sufficiently described?	1	1	1	1	1	1
2. Study design evident and appropriate?	1	0	1	0	1	1
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?	1	1	1	1	1	1
4. Subject (and comparison group, if applicable) characteristics sufficiently described?	1	1	1	2	0	2
5. If interventional and random allocation was possible, was it described?	N/A	N/A	N/A	N/A	N/A	N/A
6. If interventional and blinding of investigators was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A
7. If interventional and blinding of subjects was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?	1	1	1	1	1	1
9. Sample size appropriate?	0	1	0	1	0	0
10. Analytic methods described/justified and appropriate?	0	1	0	2	0	0
11. Some estimate of variance is reported for the main results?	0	0	0	1	0	0
12. Controlled for confounding?	N/A	N/A	0	N/A	N/A	N/A
13. Results reported in sufficient detail?	1	1	1	2	1	1
14. Conclusions supported by the results?	1	1	1	1	1	1
Total score/total possible score: Summary score: Quality rating:	7/20 (0.35) Low quality	8/20 (0.40) Low quality	7/22 (0.31) Low quality	12/20 (0.60) Moderate quality	6/20 (0.30) Low quality	8/20 (0.40) Low quality

Quality appraisal for qualitative papers

Five papers were reviewed using the qualitative QualSyst tool (Table 7). Studies scored between 0.45-0.90, indicating that there was a range of low, moderate and high-quality qualitative studies. The two mixed-methods papers were the lowest scoring of the qualitative studies overall, however, it is possible that this reflects poor reporting due to word count limitations rather than poor conduct.

The research question/objective was sufficiently described for most studies; the design was also easily identifiable and appropriate for most studies and the context/setting was clear for the most part. All provided a clear theoretical framework, which informed the study, however, all had somewhat limited descriptions about the sampling strategy used. Data collection methods were adequately described and systematic for most studies. Description of analytic methods was an area of strength for Roscoe et al. (2016) and Thomson and Johnson (2017), whilst this was less clear for the other studies. Similarly, Roscoe et al. (2016) and Thomson and Johnson (2017) were the only studies to report verification procedures to establish credibility of the study; this included ‘member checking’ and the use of a second reviewer. Conclusions appeared to be somewhat supported by the data for the majority of studies, however Roscoe et al. (2016) was the only study to make links to wider theory. Studies did not provide a reflexive account or consider possible sources of influence on the data. Roscoe et al. (2016) was the only study to mention potential sources of bias, but the likely impact of these was not discussed.

Table 7. Quality checklist ratings for qualitative studies

	Hall et al. (2013)	Crossland et al. (2017)	Roscoe et al. (2016)	Johnson & Thomson (2016)	Thomson & Johnson (2017)
1. Question / objective sufficiently described?	1	1	2	2	2
2. Study design evident and appropriate?	1	1	2	2	2
3. Context for the study clear?	1	2	2	2	2
4. Connection to a theoretical framework / wider body of knowledge?	2	2	2	2	2
5. Sampling strategy described, relevant and justified?	1	1	1	1	1
6. Data collection methods clearly described and systematic?	1	1	2	2	2
7. Data analysis clearly described and systematic?	1	1	2	1	2
8. Use of verification procedure(s) to establish credibility?	0	0	2	0	2
9. Conclusions supported by the results?	1	1	2	1	1
10. Reflexivity of the account?	0	0	1	0	0
Total score/total possible score: Summary score: Quality rating:	9/20 (0.45) Low quality	10/20 (0.50) Low quality	18/20 (0.90) High quality	13/20 (0.65) Moderate quality	16/20 (0.80) High quality

Consideration of study quality for the current review

When taking the quality ratings into account and considering the hierarchy of evidence, this is indicative that all quantitative studies were ‘low quality’. Similarly, whilst the quality of some qualitative studies appeared to be somewhat higher, qualitive studies are often considered to be a lower ‘level of evidence’ when compared to other study designs (Ackley et al., 2008). For the purpose of this review, all studies were included, however, given the low quality of the majority of studies, any conclusions made will be tentative and should be held with caution.

Study characteristics

Sample

The total number of participants included across the studies was 119. Morrissey and Ingamells (2011) referred to a 'waiting list' control group, which accounted for 5 participants. Two of the studies utilised the same participants (Johnson & Thomson, 2016; Thomson & Johnson, 2017); these participants have therefore only been included once in the total number. Consideration was given to excluding one of these papers, as they draw on some of the same qualitative data, however, as the focus of the papers were different, and the results provided different insights into outcomes following DBT, both papers were included. Sample sizes ranged from 1 to 40.

Settings

Seven of the studies were conducted in community settings (Baille & Slater, 2014; Brown et al., 2013; Lew et al., 2006; Crossland et al., 2017; Hall et al., 2013; Florez & Bethay, 2017; McNair et al., 2015), five were in forensic settings (Sakdalan et al., 2010; Morrissey & Ingamells, 2011; Ashworth et al., 2017; Thomson & Johnson, 2017; Johnson & Thomson 2016) and one was in an inpatient setting (Roscoe et al., 2016). Nine of the studies were carried out in the UK, three took place in the USA and one in New Zealand.

Participant characteristics

Demographic information

The reporting of pertinent demographic information was variable across studies. Demographic details and other relevant information about the control group referred to by Morrissey and Ingamells (2011) was not provided.

Hall et al. (2013) was the only study which did not describe the gender of the participants. From the available information, 61 (57%) participants were male and 46 (43%) were female.

The age of participants was not provided in six studies (Baillie & Slater, 2014; Morrissey & Ingamells, 2011; Hall et al., 2013; Thomson & Johnson, 2017; Johnson & Thomson, 2016; Ashworth et al., 2017). Sakdalan et al. (2010) only provided the ages for the 6 participants who completed treatment. From the available data, ages ranged from 18 to 63.

Only four studies provided information regarding the ethnicity of the participants (Sakdalan et al., 2010; Florez & Bethay, 2017; Crossland et al., 2017; Roscoe et al., 2016), with Sakdalan et al. (2010) again only providing this for the 6 treatment completers. The available data showed that 13 were White British, 1 was Caucasian, 1 was White (other), 4 were New Zealand European, 1 was Maori and 1 was Pacific Islander.

Intellectual Disability

Five studies stated that participants had ‘mild ID’ (Morrissey & Ingamells, 2011; Florez & Bethay, 2017; Ashworth et al., 2017; Crossland et al., 2017; Roscoe et al., 2016) and four described participants in the ‘mild’ and ‘moderate’ range (Baillie & Slater, 2014; Lew et al., 2006; Brown et al., 2013; Sakdalan et al., 2010). Three studies stated that participants had ‘intellectual disabilities’, however no further description was given (Hall et al., 2013; Johnson & Thomson, 2016; Thomson & Johnson, 2017) and one of the participants presented by McNair et al. (2015) was described as having ‘suspected’ intellectual disabilities. There was limited reporting across studies on the method of ID classification.

Personality disorder

Seven studies reported on the number of participants who had a diagnosis of PD or met criteria for PD (N=35) (Ashworth et al., 2017; Baillie & Slater, 2014; Roscoe et al., 2016; Brown et al., 2013; Crossland et al., 2017; Lew et al., 2006; Morrissey & Ingamells, 2011). Of these 35 individuals, 23 had BPD, 1 had Dependent PD and 11 had ‘personality disorder’ (not specified by the author). The methods used for providing a PD diagnosis were not described by studies. Thomson and Johnson (2017) reported that many women in their service had a dual diagnosis of ID and BPD but provided no further information. The remaining studies did not provide information regarding PD diagnosis.

Other diagnoses and presenting difficulties

Six studies provided information regarding other relevant psychiatric diagnoses for the study participants (Baille & Slater, 2014; Florez & Bethay, 2017; Roscoe et al., 2016; Lew et al., 2006; Brown et al., 2013; Crossland et al., 2017). Diagnoses included mood disorders, anxiety disorders, psychotic disorders, intermittent explosive disorder (IED), autism spectrum disorder (ASD) and ADHD.

There was inconsistent reporting of participants presenting difficulties across studies. Three studies did not refer to the difficulties study participants were experiencing (Johnson & Thomson, 2016; Thomson & Johnson, 2017; Roscoe et al., 2016), whilst seven studies provided this information (Sakdalan et al., 2010; McNair et al., 2015; Lew et al., 2006; Ashworth et al., 2017; Baillie & Slater, 2014; Florez & Bethay, 2017; Brown et al., 2013). The most common difficulties included problems with emotional regulation, risk to self (i.e. self-injury, suicide attempts) and risk to others (i.e. aggression, violence).

Three studies described the inclusion criteria for clients being referred to DBT (Crossland et al., 2017; Hall et al., 2013; Morrissey & Ingamells, 2011). This criterion included difficulties with emotional regulation and managing crisis and interpersonal difficulties.

Intervention characteristics

Relevant information regarding the DBT interventions was not consistently reported. However, it was evident that the interventions varied significantly, with vast differences in treatment length. Sakdalan et al. (2010) described the shortest treatment duration (13 weeks), whilst Brown et al. (2013) described the longest duration (mean treatment length of 6.9 years). It was unclear why the treatment was considerably longer for Brown et al. (2013) compared to the other studies.

All studies utilised a DBT skills group and the available data suggested that sessions were delivered weekly. Some of studies noted that the group was repeated by participants in order to consolidate knowledge/skills. For instance, Lew et al. (2006) stated that participants attended 3 cycles of their 23 week-programme. Participants in three studies received some/all of the group skills material on an individual basis (Florez & Bethay, 2017; Ashworth et al., 2017; Lew et al., 2006). Two studies provided the group skills training as a stand-alone intervention (Sakdalan, et al. 2010; Crossland et al., 2017).

Most studies drew on the DBT skills training manual (Linehan, 1993b) and made relevant adaptions. This included adapted diary cards and handouts, utilising simplified language and greater use of images; repetition, shorter sessions and greater creativity in sessions (i.e. games, roleplays, experiential exercises). Three studies reported that clients attended the group sessions with family/carers/staff (Lew et al., 2006; Sakdalan et al., 2010; Crossland et al., 2017).

Brown et al. (2013) was the only study to use DBT-Skills System (DBT-SS) (a simplified DBT-based coping skills curriculum for individuals with ID/D developed by Brown (2011)). In addition to DBT-SS, participants in that study who had histories of sexual offending also received a further weekly group in relation to this. Ashworth et al. (2017) used the “I Can Feel Good” programme (adapted DBT programme developed by Ingamells and Morrissey (2014) for the forensic male ID population).

With the exception of Sakdalan et al. (2010) and Crossland et al. (2017), the majority of participants received individual therapy sessions. Most studies provided little or no information about the individual sessions; available data indicated that they were delivered weekly.

Only two studies provided telephone coaching (Lew et al., 2006; Baille & Slater, 2014). However, many studies stated that staff members/carers were available to provide support as an alternative to telephone support.

Team consultation was not reported by four studies (McNair et al., 2015; Crossland et al., 2017; Roscoe et al., 2016; Thomson & Johnson, 2017). Where reported, the frequency of team consultation ranged from weekly, to every 4-6 weeks.

A number of studies described ‘structuring the environment’ to support clients with generalising their skills. This included providing teaching/training/groups for family/carers/staff around DBT (Lew et al., 2006; Brown et al., 2013; Baille & Slater,

2014; Sakdalan et al., 2010; Thomson & Johnson, 2017; Florez & Bethay, 2017) and consultation with the staff teams (Brown et al., 2013; Baille & Slater, 2014; Lew et al., 2006).

Outcome measurement

The evaluation methods used to measure outcomes following DBT varied widely across the studies.

Seven studies used carer/staff-completed and/or self-report psychometric tools, many of which had been adapted or specifically designed for people with ID (Morrissey & Ingamells, 2011; Baillie & Slater, 2014; Sakdalan et al., 2010; Lew et al., 2006; Crossland et al., 2017; Ashworth et al., 2017; Hall et al., 2013). These tools were largely used to measure risk, symptomology, functioning, wellbeing, and psychological distress. Sakdalan et al. (2010) also asked participants to complete a 9-item questionnaire to assess their learning and elicit feedback following the intervention.

Five studies referred to monitoring the frequency of incidents e.g. harm to self and others (Morrissey & Ingamells, 2011; Sakdalan et al., 2010; Florez & Bethay, 2017; Brown et al., 2013; Thomson & Johnson, 2017). This information was collected primarily through the use of incident reports.

McNair et al. (2015) argued that measures commonly focus on incident and symptom reduction rather than psychological change. They therefore utilised repertory grid

technique, based on Personal Construct Psychology (PCP) (Kelly, 1955) to measure changes in 'construing', self-esteem and 'implicative dilemmas' about self. Construing involves identifying 'elements' (e.g. important people, the self, ideal self) which can be described using constructs (e.g. funny, boring) and considering whether the elements are similar or different. Individuals who are less able to adapt their construing when presented with new information, are seen as having 'tighter construing' and this has been linked to greater psychological distress (Feixas-Viaplana, Cipriano & Dominguez, 2007). Implicative dilemmas occur when a positive change on one construct is associated with an undesired change on another.

Four studies conducted semi-structured interviews with participants following DBT (Crossland et al. 2017; Hall et al., 2013; Roscoe et al., 2016; Thomson & Johnson, 2017). It is important to note that it was not the aim of these studies to use qualitative interviews as a method for capturing treatment outcomes specifically; for many studies, this information appeared to be elicited as a natural consequence of participants being interviewed about their views and experiences of DBT more broadly.

Some studies did not conduct formal interviews, however qualitative information regarding outcomes was captured through staff/therapist's observations and service-user descriptions (Florez & Bethay, 2017).

Two studies referred to secondary outcomes, including changes in the level of secure setting required and number of days hospitalised (Morissey & Ingamells, 2011; Brown et

al., 2013). Anecdotally, Baillie and Slater (2014) suggested that outcomes could be evaluated by assessing the *costs saved* in relation to the setting/accommodation participants required.

DBT Outcomes

Various outcomes following DBT were described across the studies. These have been synthesised and presented below.

Risk and behavioural change

Outcomes in relation to risk and behaviours which challenge were reported most commonly across the studies. A small number of studies utilised psychometric tools to measure this. For Sakdalan et al. (2010), the Short-Term Assessment of Risk and Treatability (START) (Webster et al., 2004) measure was completed by keyworkers, pre and post treatment to assess 'risk' and 'strength' domains. Findings suggest significant reductions in risk ($p < 0.05$) and significant improvements in strengths ($p < 0.01$). No further descriptions were provided.

Lew et al. (2006) adapted the Youth Risk Behaviour Survey (RBS) (Centers for Disease Control and Prevention, 2001) and used 22 of the 87 items from this measure, which were regarded as being most relevant to people with ID; however, information about the specific questions selected was not reported. The RBS was completed by 3-5 team members at baseline, 6-months, 12-months and 18-month intervals. Results suggested that risk behaviours appeared to get worse between baseline and the 6-month interval

('incidents of worsening'= 54%, 'incidents of no change'= 16%, 'incidents of improvements'= 30%). At 12-months, risk behaviours had improved by 60% compared to baseline, 22% stayed the same and 18% had worsened. This pattern of improvement was maintained at 18 months. Authors highlighted a slow but gradual decrease in the number of individuals self-harming from baseline (n=6) to 18-months (n=2).

Ashworth et al. (2017) captured relevant risk information for 'Mr C' within the Emotional Problems Scale-Behaviour Report Scale (EPS-BRS) (Prout & Strohmer, 1991). This was a self-report measure completed at initial assessment, pre-treatment and post-treatment. At the end of treatment, results suggested that little change had occurred. Authors noted that this measure indicated 'overall risk maintenance'.

Many studies referred to the frequency of incidents (e.g. harm to self/others). For Brown et al. (2013), 'challenging behaviours' were recorded in incident reports and classified using a system of three intensity levels: 'Red Flags' (e.g. shouting, swearing), 'Dangerous situations' (e.g. threats of violence) and 'Lapses' (e.g. self-harm, aggression). Behaviours were categorised by the support staff observing the behaviour or later classified by the clinical team. Inter-rater reliability was not reported. Outcomes were described across 4 years of treatment, however authors indicated that data was available for significantly longer than this (M=6.9 years). Results indicated that there was a significant reduction across all 3 categories (red flags ($p < .001$), dangerous situations ($p < .003$), lapses ($p < .001$)); most improvement occurred in the first year and these improvements were maintained in subsequent years, but the statistical significance was

less robust. The more severe behaviours appeared to improve more gradually over the 4 years compared to the less severe behaviours. Authors identified the presence of BPD, self-injury and aggression as predictors of better outcomes, whilst IED was a predictor of slower progress. Authors also highlighted that there was a reduction in hospital admissions and time spent in secure settings in the first two years of treatment, compared to the two years prior to treatment.

Both Sakdalan et al. (2010) and Florez and Bethay (2017) established a 3-month baseline of incidents prior to treatment and then monitored incidents throughout treatment. Sakdalan et al. (2010) asked vocational and residential staff to provide incident reports, however as only the vocational service supplied this, data was thought to be compromised and was therefore not reported in the study. Florez and Bethay (2017) operationalised the 'target behaviours' (uncooperative behaviour, aggression, self-injury, and elopement) and specified that their frequency was monitored weekly over the 1-year duration of treatment. Results indicated that there was a decrease in the frequency of behaviours, with periods of zero frequency during treatment and for the final 3 months of treatment. The intensity and duration of the behaviours which *did* occur, had also reduced significantly in comparison to past episodes. In the 12 months following treatment, 'Gaby' was able to maintain an average of <1 challenging behaviour a month.

Morissey and Ingamells (2011) stated that 25 individuals had completed DBT, however outcomes were only provided for 6. The study referred to using data on incidents of self-

harm and aggression, but no further detail was provided around how this was carried out. Results indicated that no significant differences were found in incidents of aggressive behaviour, however authors noted that due to being in a highly controlled hospital setting, the baseline was low. In the 12 months following treatment, individuals who received DBT were more likely to be moved to lower security settings (four out of six), compared to the waiting list control group (one out of five); suggesting that clinicians perceived a reduction in risk. It was reported that all four were able to remain in less secure settings.

Thomson and Johnson (2017) explained that quantitative data for service evaluation was collected throughout the programme and results from this indicated a reduction in incidents of aggression and self-injury. No further information was provided.

McNair et al. (2015) did not directly refer to measuring the frequency of incidents, however a reduction in self-harm was reported as a treatment goal for both the participants. There appeared to be a reduction in self-harm for ‘Sarah’, who reported self-harming on ‘only two occasions’ throughout treatment, however there was no baseline comparison. Comparatively, ‘Laura’ presented with continued high levels of self-harm, which occurred ‘up to nine times per week’. However, ‘Laura’ had periods of non-attendance with DBT and authors suggested it was therefore not possible to accurately measure behavioural change.

Qualitative outcomes in relation to risk were reported by three studies via semi-structured interviews. For Hall et al. (2013), findings suggested that participants were managing problems by less destructive means; one individual reported a reduction in self-harm, whilst another reported being in trouble with the police less. In the study by Johnson and Thomson (2016) staff indicated that due to a reduction in risk, a client had been granted leave from the forensic facility; this was significant as the client had not been given leave in 29 years.

Functioning, psychological distress and wellbeing

Five studies used a range of psychometric tools to measure functioning, psychological distress, symptomology and wellbeing. For Sakdalan et al. (2010), key workers completed the coping skills subdomain of the Vineland Adaptive Behaviour Scales–Second Edition (VABS-II) (Sparrow et al., 2005) and the Health of the Nation Outcome Scales for people with learning disabilities (HONOS-LD) (Wing et al., 1996) pre and post treatment, as a measure of coping skills and global functioning respectively. Improvements in coping skills were noted but these were not significant, however there were significant improvements in global functioning ($p< 0.05$).

Crossland et al. (2017) also utilised the HoNOS-LD, however this was administered with the individual and their support worker. The Psychological Therapies Outcome Scales—Intellectual Disabilities (PTOS-ID) (Beail, Vlissides, & Jackson, 2015) was used to measure overall positive wellbeing and psychological distress. Measures were completed pre-treatment, post-treatment and at 4-month follow up. Scores decreased on

HoNOS, suggesting improvements in overall functioning. There was an increase in scores between post-group and 4-month follow up for 2 participants, but all scores were lower overall at follow up compared to baseline. Scores on the PTOS-ID indicated that psychological distress decreased following the group and these scores continued to decrease for 3 people when measured at follow up. 1 participant had increased scores of psychological distress at follow up compared to baseline. Positive wellbeing scores increased for all participants following the group. These improvements were maintained or improved further for 3 individuals but decreased to baseline for 1 person. Statistical analysis was not carried out; therefore, it is unclear whether these changes in scores were significant.

Morrissey and Ingamells (2011) reported 'significant' reductions on the self-report Global Severity of Distress Scale of the Brief Symptoms Inventory (BSI) (Derogatis 1993), however statistical analysis was not reported. Despite utilising numerous other measures, only outcomes for the BSI were referred to. Similarly, Baillie and Slater (2014) described using psychometric tools, however outcome data was not provided. Baillie and Slater (2014) critiqued some of the measures used (e.g. sensitivity to measure psychological change) and also referred to having insufficient 'client numbers' to carry out statistical analysis.

Hall et al. (2013) utilised the Glasgow Depression Scale (GDS) (Cuthill, Espie & Cooper, 2003) and Glasgow Anxiety Scale (GAS) (Mindham & Espie, 2003) to measure depression and anxiety symptomology respectively. Measures were completed at the

start and end of treatment, but no further detail was given. There was a reduction in anxiety and depression scores at the end of treatment; GDS scores decreased from above to below the clinical cut off, whilst GAS scores decreased, but still remained above the clinical cut off. Authors noted that statistical analysis was not carried out, due to the small sample size.

Qualitative outcomes were provided by two studies. In the study by Florez and Bethay (2017) staff members observed an improvement in mood for 'Gaby'. For Roscoe et al. (2016), one participant reflected on a decrease in affect-related scores within her diary card and saw this as indicative of improvement.

DBT Skills

Across all qualitative studies, participants described the skills/strategies they had learnt and been able to apply. Participants reported being able to generalise skills in their day to day life (Crossland et al. 2017) and utilise particular skills to manage difficult feelings and situations (Roscoe et al., 2016; Thomson & Johnson, 2017; Johnson & Thomson, 2016; Florez & Bethay, 2017; McNair et al., 2015). Many reported being able to develop skills which were personalised and meaningful to them (Hall et al., 2013; Roscoe et al., 2016; Thomson & Johnson, 2017). Some reported continuing to use their skills, or an intention to continue skill use following treatment completion (Hall et al., 2013; Thomson & Johnson, 2017). However, some individuals experienced difficulties generalising and utilising skills (Crossland et al. 2017); some appeared to struggle with recalling the DBT skills (Roscoe et al., 2016; Crossland, et al. 2017), whilst inconsistent staff

support/knowledge appeared to be a barrier to effective skill generalisation for other individuals (Thomson & Johnson, 2017).

Some quantitative studies also referred to the measurement of DBT skills. Baillie and Slater (2014) described developing tool to measure DBT skill use, however, as previously noted, outcome data was not reported. Sakdalan et al. (2010) used a DBT assessment form at the end of treatment and participants were scoring within the moderate-high range, suggesting that they had learnt the principles of DBT; qualitative feedback also indicated that they had 'learnt a lot' from the course.

In addition to describing general 'skill use', participants also referred to outcomes in relation to the specific DBT skills modules (emotional regulation, mindfulness, interpersonal effectiveness, distress tolerance). Ashworth et al. (2017) was the only study to complete psychometric tools to measure change associated with each of these modules. In relation to *emotional regulation*, the Emotional Control Questionnaire (ECQ) (Roger & Najarian, 1989) completed pre and post treatment, demonstrated no improvements with self-reported emotional control strategies. Qualitative data from three studies indicated that participants experienced increased control of emotions, had more balanced reactions and generally felt 'calmer' (Hall et al., 2013; Thomson & Johnson, 2017; Roscoe et al., 2016). For Florez and Bethay (2017), both 'Gaby' and staff members reported greater emotional awareness, and staff also observed improved emotional regulation. Anecdotally, Morrissey and Ingamells (2011) indicated that participants had increased emotion regulation skills; they associated this change with

reduced seriousness of self-injury and interpersonal aggression. Similarly, Baillie and Slater (2014) anecdotally indicated that participants had developed emotional regulation and distress tolerance skills.

In relation to *distress tolerance*, Ashworth et al. (2017) utilised the self-report Coping Response Inventory (CRI) (Moos, 1993) pre and post treatment. Results indicated that 'Mr C' was less likely to use maladaptive coping strategies, however he was also less likely to use more positive coping strategies. For Florez and Bethay (2017), both 'Gaby' and staff observed greater confidence when dealing with crisis.

In relation to *mindfulness*, both Hall et al. (2013) and Ashworth et al. (2017) utilised the Cognitive and Affective Mindfulness Scale–Revised (CAMS-R) (Feldman et al., 2007) pre and post treatment. Both studies reported an increase in scores, indicating improved mindfulness skills and attitudes of acceptance. However, staff in the study by Ashworth et al. (2017) also completed this measure in relation to 'Mr C' and they did not report an improvement.

In relation to *interpersonal effectiveness,* Ashworth et al. (2017) used the Chart of Interpersonal Reactions in Closed Living Environments (CIRCLE) (Blackburn & Renwick, 1996), which is an observational scale completed by staff at initial assessment, pre-programme and post-programme. Changes on the scale at the end of treatment indicated a shift towards a more negative interpersonal style. However, authors noted that 'Mr C' was being 'nursed in isolation' for part of therapy and post-treatment;

measures of interpersonal effectiveness may therefore reflect the lack of social interactions. Qualitative data from Roscoe et al. (2016) indicated that participants experienced better communication, negotiation and relationship skills. Other qualitative studies highlighted that participants reported developing relationships within the group (Thomson & Johnson, 2017; Crossland et al., 2017; Johnson & Thomson, 2016). For Thomson and Johnson (2017), a decrease in aggressive incidents was associated with improved relationships with the ward staff.

Psychological change

McNair et al. (2015) was the only study to utilise repertory grids pre and post treatment. Results indicated that at the end of treatment, 'Sarah' experienced clinically significant improvements in self-esteem, some changes in her construing and a decrease in implicative dilemmas about self; whilst 'Laura' had continued low self-esteem, there was little change in construing and an increase in implicative dilemmas about self was observed.

'A life worth living'

Participants in two studies appeared to have developed a greater sense of self-worth following DBT; data suggested that they were hopeful for the future and were on a journey towards 'a life worth living' (Thomson & Johnson, 2017; Johnson & Thomson, 2016).

Financial outcomes

Two studies referred to costs saved in relation to individuals attending DBT. Baillie and Slater (2014) highlighted that 8 individuals were close to placement breakdown and may have needed to move to more costly secure accommodation, however, following DBT, 6 of these individuals were able to maintain their placements. This outcome was associated with significant costs being saved and a better quality of life for the individuals. Brown et al. (2013) compared the costs of DBT to hospital admissions and estimated that DBT resulted in savings of $491,340 per client per year.

Discussion

This systematic review aimed to review the available evidence in relation to the use of DBT for individuals with ID, with a particular focus on extracting and synthesising both quantitative and qualitative outcome data.

Key findings

Most studies indicated that there was a reduction in risk behaviours (e.g. self-harm, aggression); moreover, secondary outcomes in relation to risk included fewer hospital admissions, moving to less secure settings, maintaining placements and being granted leave. When a reduction in risk behaviours was not observed, this was primarily at an individual level (e.g. Ashworth et al., 2017; McNair et al., 2015) and authors mainly attributed this to poor treatment attendance or a low baseline of incidents. The risk reductions observed reflected outcomes reported in the wider population (Linehan, et al. 1991; Linehan, et al. 2006; Turner 2000). However, ID papers appear to report on self-injury or aggression behaviours predominantly, whilst suicidality was rarely reported. Baillie and Slater (2014) suggest that standard DBT behavioural indices, such as the number of suicide attempts, are not relevant to many individuals with ID, as the base rate is generally low.

Findings from the review also indicated that participants experienced improvements in global functioning, wellbeing, symptomology and reduction in psychological distress. These positive outcomes also echo some of the findings in the wider literature (Clarkin

et al., 2007; Wilks et al., 2015). As noted similarly above, when these outcomes were not observed within studies, this was largely at an individual level, highlighting the need for larger scale studies.

Other key findings included the application and generalisation of DBT skills to manage difficult situations and emotions; however, some difficulties with utilising the skills were acknowledged. This provides a novel insight into outcomes related to *DBT skills use* specifically, as this area does not appear to be as readily captured within the literature. Neacsiu et al. (2010) argued that despite skills training being a crucial part of DBT, there is a lack of reliable and valid DBT skills use measures, making it difficult to examine DBT skills use as an outcome.

DBT attempts to help a client build a 'life worth living' (Linehan, 1993); working towards a life worth living and feeling hopeful for the future, was described by two studies. However, these two studies drew on the same participant data, so it may be more appropriate to suggest that this was described by one group of participants.

The outcomes described in the reviewed studies are largely in line with some of the 'hierarchical behavioural targets' of DBT. For instance: decreasing life-threatening behaviours (i.e. parasuicidal acts), decreasing quality of life-interfering behaviours (i.e. depression) and increasing behavioural skills (i.e. emotional regulation, mindfulness, distress tolerance, interpersonal effectiveness) (Linehan, 1993a; Chapman, 2006). This may be indicative that DBT could be an efficacious treatment for individuals with ID.

Limitations of the studies

Due to the poor quality of the studies included in the review, we are unable to confidently conclude that DBT was responsible for any of the observed outcomes. Studies used weak designs, with small sample sizes and lacked control groups. Only one study referred to a 'waiting list' control group, but no further information was provided. There was a lack of follow up data, meaning we are uncertain as to whether any improvements were maintained over time.

The papers included in the review are subject to a number of further limitations. There was inadequate reporting of participant characteristics including age, diagnoses and level of ID; this limits our understanding of who may particularly benefit from DBT. Reporting the level of ID and diagnoses may be particularly important given that NICE (2009) recommends that individuals with mild ID and BPD, should be able to access the same services as the wider population who have BPD. The available data indicated that the majority of participants had mild ID, which is largely in line with NICE guidance, whilst a BPD diagnosis was reported for a smaller number of participants. This is perhaps unsurprising, given the difficulties previously noted with providing a diagnosis of PD/BPD to individuals with ID (Cowan, 2018).

The reporting of relevant intervention information was also lacking, making future replication of the therapy difficult. Moreover, there were significant variations in the treatment delivered (i.e. treatment duration, modalities), we may therefore question fidelity to the model.

Similarly, there were considerable variations in the methods used to evaluate outcomes, which presents a challenge when attempting to compare studies. It is acknowledged that there is generally a lack of valid and reliable therapy outcome measures for individuals with ID (Skelly, 2011). Some studies in this review utilised validated ID measures, whilst others made adaptions to standardised tools, potentially limiting their reliability. Many studies relied on staff reporting of incidents, however, research suggests that staff frequently under-report incidents (van den Bogaard et al., 2018; Tenneij et al., 2009), increasing the likelihood of bias. Additionally, staff can only report on observable behaviour and are unable to understand internal processes for clients (Ashworth et al. 2017).

The majority of studies did not conduct statistical analyses; therefore, it was unknown whether reductions in scores represented significant changes. Additionally, some outcome data appeared to be selectively reported; for instance, Morrissey and Ingamells (2011) reported that 25 participants had completed treatment, but only described outcomes for 6. Whilst authors provided some rationale for this (e.g. difficulties analysing outcomes at a group level due to variations between participants and concurrent treatments being received), this could be indicative of bias within studies (Kirkham et al., 2018).

Critique of the current review

By drawing on both qualitative and quantitative literature, this review provided a unique and novel understanding of the outcomes following DBT for individuals with ID. Eight of

the studies examined were not included in the previous review, enabling further insight into this research area.

However, the inclusion/exclusion criteria applied may have resulted in the exclusion of papers which could have provided important findings (e.g. dissertation papers). Moreover, two papers included by McNair et al. (2017) were excluded in this review, as they utilised an adolescent population. In order to facilitate greater homogeneity across the sample, only studies which involved adults with ID were included; however, given the considerable differences across studies (i.e. settings, interventions), the sample is likely to be heterogenous.

The quality appraisal tool selected enabled a range of study designs, including qualitative and quantitative papers to be appraised using the same criteria, meaning useful comparisons between studies could be made. However, the tool did not account for the 'hierarchy of evidence', meaning there was a risk of overinflating the overall quality of the papers.

Outcome data from a range of studies was extracted and effectively synthesised, guiding the reader through the various outcomes in a coherent manner. However, from the way the outcome data was categorised and presented, it could be inferred that these outcomes exist in isolation, when it may be more likely that they are intrinsically linked. For instance, the link between increased emotional regulation skills and reduced self-injury/aggression (Morrissey & Ingamells, 2011).

Clinical implications and future research

Generalising skills and restructuring the environment are important components of DBT (Linehan, 2015); utilising carers/staff/family to help facilitate this may be particularly important for people with ID. Lack of staff knowledge, support and co-operation appeared to hinder the generalisation of skills and the appropriate reinforcement of skilful behaviours (Baillie & Slater, 2014; Thomson & Johnson, 2017). Therefore, ensuring that those around the individual have an adequate understanding of DBT and are invested in the model, may contribute to positive outcomes.

Consideration should be given as to who may benefit particularly from DBT, given the difficulties with providing a formal BPD diagnosis within this population. Baillie and Slater (2014) suggest that a more appropriate way of considering who DBT is suitable for involves looking at behavioural indicators of emotional dysregulation (e.g. engaging in risky behaviours), rather than looking to a formal diagnostic criterion for BPD.

Given the considerable variations in the DBT treatment received, the development of a manualised DBT programme for individuals with ID would be beneficial. This would facilitate more consistent treatment delivery, enabling better monitoring of therapy adherence/fidelity and more effective comparisons across studies.

There is a need to develop standardised outcome measures which have been adapted for this population; measures could then be consistently applied across studies, facilitating more effective comparisons of outcomes. As skills use was highlighted as a

key outcome within these studies, the development of a standardised way to measure skill use and the impact of this, would be beneficial (Valentine et al., 2014). As previously acknowledged, there are difficulties with relying on staff report data, however, there are also difficulties with utilising self-report measures with people with ID (Emerson, Felce & Stancliffe, 2013). A balance should therefore be established, whereby a combination of staff observation and self-report data are utilised.

RCTs represent the 'gold' standard for evaluating effectiveness in treatment interventions, however RCTs are uncommon in ID literature and are fraught with practical and methodological challenges (e.g. recruiting an adequately sized and representative sample) (Mulhall et al., 2018). Conducting an RCT in this research area may present a challenge currently, however there is a clear need to develop the evidence base. Future research should endeavor to utilise more rigorous study designs, including adequate sample sizes and random allocation to a control or treatment group. This would enable us to more confidently attribute any outcomes to the treatment received, and the effectiveness of DBT for people with ID could then be evaluated.

Given the infancy of this research area, it may also be beneficial to carry out further qualitative research, in order to understand the *experiences* of individuals with ID who have received DBT. Conducting this type of research may facilitate greater insight into what components within DBT were most useful, and whether further adaptations are required. Some of the qualitative studies included in this review explored experiences of the DBT programme within inpatient and forensic settings (Roscoe et al., 2016;

Thomson & Johnson, 2017); however, no study to date has examined experiences of the DBT programme within a community setting. It may therefore be particularly beneficial for future research to explore experiences of a community-based DBT programme for individuals with ID.

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CHAPTER 2

EMPIRICAL PAPER

EXPERIENCES OF DIALECTICAL BEHAVIOUR THERAPY IN A COMMUNITY SETTING FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

Abstract

Background: Individuals with intellectual disabilities (ID) are often excluded from qualitative research and there is a paucity of studies exploring their views and experiences of psychological interventions. There is growing interest in the application of Dialectical Behaviour Therapy (DBT) for individuals with ID and recent qualitative studies have explored their experiences of DBT in inpatient and forensic settings. This paper aimed to explore experiences of DBT in a community setting for people with ID.

Method: Eleven individuals recruited from two NHS Trusts were interviewed about their experiences of DBT. Interview data was analysed using Interpretative Phenomenological Analysis (IPA).

Results: Four superordinate themes and nine subordinate themes emerged from the data. The first superordinate theme *'experience of power'* captured participants experience of power within DBT, whereby individuals described having a voice and appeared to experience a shift in their sense of power. The second theme *'differences in therapy contexts'* highlighted how participants had made sense of the different therapeutic contexts (i.e. individual sessions, group sessions), how these modalities met different needs and the associated challenges/rewards experienced. The third theme *'the experience of a positive therapeutic relationship'* focused on the qualities and attitudes of the therapist, which contributed to the development of a positive therapeutic

relationship. The fourth theme *'a new way of being'* described the impact DBT had on participants' everyday lives and the shift in their sense of self.

Discussion: This study provides insight into the lived experiences of people with ID receiving DBT. Therapeutic processes including the interplay between factors unique to DBT and features common across therapies are discussed. Limitations of the study, clinical implications and future recommendations are considered.

Introduction

Dialectical Behaviour Therapy

Dialectical Behaviour Therapy (DBT) (Linehan, 1993) is a well-established and evidence-based treatment for Borderline Personality Disorder (Chapman, 2006). The DBT model draws on Biosocial Theory and posits that individuals experience the difficulties associated with BPD (i.e. cognitive, emotional and behavioural dysregulation, interpersonal difficulties) as a result of the interplay between 'biological vulnerabilities' (e.g. heightened emotional sensitivity) and growing up in a 'invalidating environment' (e.g. erratic, inappropriate or extreme responses from others when private experiences are communicated) (Feigenbaum, 2007; Crowell, Beauchaine & Linehan, 2009). Individuals with BPD have often not been able to develop effective skills in regulating their emotions and tolerating distress and may therefore engage in impulsive behaviours (e.g. parasuicidal acts) as a way of managing overwhelming feelings (Lippold, 2016).

Grounded in a 'dialectical philosophy', DBT encourages the balance and synthesis of both 'acceptance' *and* 'change' principles; meaning an individual's difficult experiences are validated, and they are also encouraged to develop more adaptive cognitive and behavioural coping strategies (Swales, 2009).

Originally developed as an outpatient intervention, DBT utilises a multi-modal approach, including group skills training, individual therapy, 24-hour telephone coaching and team consultation (Linehan et al., 2015). Within the group component, individuals are supported to develop skills in the following areas: emotional regulation, distress

tolerance, interpersonal effectiveness and mindfulness (Linehan, 2015). 'Standard' DBT is usually 1-year in duration; one cycle of group skills training is around 24 weeks, and this is then repeated (Flynn et al., 2017).

The efficacy and effectiveness of DBT for individuals with BPD has been supported by the research literature; in a meta-analysis by Kliem et al. (2010), a moderate effect size for a reduction in suicidal and self-injurious behaviours was found. Similarly, a meta-analysis conducted by Panos et al. (2014) concluded that DBT was an efficacious treatment in reducing suicidal and self-harming acts in individual's with BPD.

Qualitative research

Elliott (2008) argues that exploring client experiences of therapy is central to advancing our theoretical understanding, particularly in relation to how therapeutic processes translate into change. Understanding client experiences of therapy can lead to more effective interventions and give individuals a voice (Timulak & Keogh, 2017; McElvaney & Timulak, 2013).

Little, Tickle and das Nair (2017) conducted a review of the literature exploring experiences of DBT for individuals with BPD in the general population. This utilised a meta-ethnographic approach and four main themes were identified: *'life before DBT'* (i.e. feelings of hopelessness, not feeling understood or supported*), 'the relationships that support change'* (i.e. the therapeutic relationship, relationships with similar individuals in

the group), *'developing self-efficacy'* (i.e. having the skills to manage emotions, taking ownership/responsibility) and *'a shift in perspectives'* (i.e. greater insight and acceptance around difficulties, feeling hopeful for the future).

Historically, the views and experiences of people with ID have been largely overlooked and these individuals were scarcely included in qualitative research (Cookson & Dickson, 2010). Features associated with this population such as 'inarticulateness', 'unresponsiveness' and having a concrete frame of reference (Booth & Booth, 1996) potentially make it more difficult for these individuals to tell their story during interviews. However, researchers are increasingly utilising methodological adaptions to better engage with individuals with ID and enhance research interviews (Hollomotz, 2018). Moreover, there is greater recognition that the views and experiences of people with ID are valuable, 'worth hearing' and 'worth understanding' (Nind, 2008; Hoole & Morgan, 2010). This shift is reflected in a review conducted by Beail and Williams (2014), which found a significant increase in the number of published qualitative research papers involving people with ID. However, they acknowledge that these papers still represent a minority of published research compared to the wider population.

DBT for individuals with intellectual disabilities

DBT has increasingly been adapted and utilised with a range of diagnoses, populations and settings (Lynch et al., 2007). In recent years there has been growing interest in DBT as a potential treatment for people with ID who present with emotional dysregulation and impulsive behaviours (Crossland, Hewitt & Walden, 2017). This growing interest is

important given the National Institute for Health and Care Excellence (2009) recommendation that individuals with mild ID and BPD, should be able to access the same services as other people with BPD.

The current evidence base for DBT and people with ID is limited, however the available studies have reported positive outcomes. Studies reported reductions in self-injury and aggression to others (Lew et al. 2006; Brown, Brown & Dibiasio, 2013); individuals also required fewer hospital admissions (Brown et al., 2013) and were able to move to lower security settings following DBT (Morrissey & Ingamells, 2011). Other outcomes included reductions in psychological distress (Crossland et al., 2017), a decrease in anxiety and depression symptoms (Hall, Craven & Woodrow, 2013), and improvements in global functioning (Sakdalan, Shaw & Collier, 2010; Crossland et al., 2017). However, these studies had various methodological limitations, including small sample sizes and a lack of control groups; we are therefore unable to confidently attribute any of the reported outcomes to the DBT intervention. McNair, Woodrow and Hare (2017) reviewed the available literature and concluded that DBT can be adapted for individuals with ID, however conclusions about efficacy or effectiveness could not confidently be made, due to the quality of the available literature. Authors noted that more methodologically robust evidence was required, and they also suggested that it would be beneficial to carry out qualitative research, in order to explore individual's experiences of DBT. It could be argued that whilst quantitative research captures important information about psychological change following an intervention, it does not capture valuable information

about the salient processes within client experiences of therapy (MacMahon et al., 2015).

At the time this research commenced, the author was only aware of one paper (Hall et al. 2013) which sought qualitative feedback from individuals with ID following DBT; however, a number of qualitative papers have subsequently been published. The growing nature of this research area suggests that the use of DBT for individuals ID is a relevant topic currently, with particular interest around how individuals experienced and made sense of the treatment. The available qualitative research within this area is presented below.

In the study by Hall et al. (2013), five individuals were interviewed following attending a community-based DBT programme. Interviews focused on experiences of the group skills component specifically, and data was analysed using Thematic Analysis. Findings suggested that individuals observed positive changes in themselves following the group (e.g. reduction in self harm) and benefitted from being with others who had similar difficulties. Mindfulness and managing crisis were highlighted as helpful components of the treatment, whilst irregular attendance from others and endings were experienced as challenging. Individuals reported being able to continue using their skills following completing the group. Participants provided suggestions for future improvements, including repeating the group twice.

Crossland et al. (2017) interviewed four individuals and their support staff about the standalone DBT skills group they attended in the community, and results were analysed using Thematic Analysis. Participants described developing relationships with others in the group; they also spoke about the boundaries of the group, including the duration and number of sessions. Some experienced difficulties with understanding and remembering the material and therefore utilised support staff when trying to recall information. Participants described generalising skills with differing levels of success. Participants made suggestions for future improvements, including conflicting accounts related to how many sessions the group should be.

The above studies used mixed-methods designs, which involved seeking qualitative feedback in addition to collecting quantitative measures; comparatively, Roscoe et al. (2016) conducted a qualitative study which used Interpretative Phenomenological Analysis (IPA) to explore ten participants' experiences of DBT in an inpatient setting. Participants reported experiencing difficulties in understanding parts of DBT, however some developed personal understandings of the different aspects of the programme. Individuals found DBT to be helpful and beneficial; they spoke about applying the skills they had learnt to manage difficult situations more effectively and described having greater control over intense emotions. Participants highlighted factors that affected their engagement in therapy; this included the number of clients present in the group skills sessions and the development of a trusting therapeutic relationship.

Thomson and Johnson (2017) used IPA to examine seven participants' experiences of DBT in a forensic setting. Participants described having a good understanding of DBT and the functions of the different modalities. They were able to develop skills which were personalised and meaningful to them. Individuals recognised the advantages of utilising DBT skills and were able to respond to difficult situations more effectively. Individuals experienced some skills as being more difficult to apply than others. Participants were able to generalise their skills outside of sessions on the ward, however they experienced inconsistencies in the level of knowledge ward staff had about DBT.

Research aims

Although the studies described above provide insight into the experiences of DBT for people with ID, further research into the lived experiences of these individuals may further enrich and compliment the available literature.

Furthermore, the two previous qualitative studies cited, explored experiences of the DBT programme within inpatient or forensic settings, whilst the two mixed-methods studies took place in community settings, gathering qualitative data about the DBT skills group component specifically, then analysed the results using Thematic Analysis. To date, the author could not identify any qualitative papers, which explored experiences of the DBT programme (i.e. multi-modal) in a community setting for individuals with ID, and analysed the data using an in-depth, rigorous analysis. This research therefore aimed to explore the subjective experiences of people with ID who received DBT in a community setting.

Method

Design

As this study aimed to explore individuals' experiences of DBT, a qualitative methodology which utilised a phenomenological stance was considered to be most appropriate; IPA was subsequently used.

IPA is committed to examining how individuals make sense of their major life experiences. The main theoretical underpinnings of IPA are phenomenology, hermeneutics and idiography. Phenomenology is concerned with an individuals' subjective, lived experience of an event. The idiographic element of IPA means that it focuses on the 'particular', therefore a detailed analysis of individuals' accounts is required. Hermeneutics refers to the interpretative component of IPA, as it is concerned with how individuals *make sense* of their personal world. During IPA, the researcher attempts to make sense of how the individual made sense of their experiences; this process is referred to as the 'double hermeneutic' (Smith, Flowers & Larkin, 2009; Smith & Eatough, 2007; Smith, 2011).

Roscoe et al. (2016) suggested that it can be difficult to accurately represent the views of individuals with ID, therefore the interpretative element of IPA may be particularly relevant and appropriate when capturing the experiences of this population. The use of IPA has also been utilised in previous research with people with ID to explore their experience of therapy (Merriman & Beail, 2009; MacMahon et al. 2015; Anslow, 2013).

Participants

Eleven participants were recruited from two community-based NHS Intellectual Disability Teams. Nine of the participants were recruited from one team and two were recruited from the other.

IPA typically requires a homogenous, small sample size, due to its idiographic commitment. Whilst 3-6 participants are generally seen as acceptable, the sample size may also depend on factors such as the richness of the individual cases (Smith et al. 2009). As individuals with ID may have difficulties expressing themselves verbally or telling their story (Beail & Williams, 2014), a larger sample of participants were recruited to account for a potential lack of rich data.

Purposive sampling was used, meaning participants were selected as they were considered to be experts in the phenomena being researched (Holloway & Wheeler, 2010). Clinicians working within the teams identified individuals who met the inclusion criteria (Table 8).

Table 8. Inclusion and exclusion criteria

Inclusion Criteria	Rationale/further information
Have an intellectual disability	As this research aimed to explore experiences of DBT for individuals with intellectual disabilities, participants were only included if they had an intellectual disability. Teams informed the author about the level of ID for each participant (i.e. mild, moderate, severe). However, as the author did not have access to participants' personal files, there is no available information regarding how ID diagnosis or any other psychiatric diagnoses were established (e.g. assessment tools used, IQ scores, information regarding social/adaptive functioning etc.)
Received DBT (including at least 1 full cycle of the group skills training)	As this research aimed to explore the experience of receiving DBT, participants needed to have received DBT in order to be able to talk about their experience of it. Research studies indicate that fidelity to the DBT treatment model varies due to factors such as the therapeutic setting and service restrictions (Baillie & Slater, 2014; Thomson & Johnson, 2017), however the group skills training appeared to be a consistent component across DBT research studies. Participants were therefore required to have completed at least 1 full cycle of the group skills training component.
Have capacity to give informed consent	Due to ethical considerations, it is important that participants are able to understand what is expected of them as part of the research and what their rights are. Capacity to provide informed consent was determined by their ability to answer the 'comprehension questions' correctly (Appendix 3).
Exclusion criteria	**Further information/rationale**
Current significant risk of harm to self or others	It may cause additional distress to ask individuals who are currently in crisis to discuss their experiences of treatment. It would also be unethical to knowingly put the participant or researcher in a potentially unsafe situation. The researcher liaised with the DBT clinicians prior to interviews about any current risk concerns and the participants readiness to take part in the research.

All participants were White British and were aged between 26-52 years old (mean= 38). Eight were females and three were males (Table 9). Ten of the participants had mild ID and one had moderate ID. The majority had a diagnosis of BPD or displayed BPD characteristics. Participants were referred to DBT for reasons including risk behaviours (e.g. self-harm, suicide attempts, aggression to others) emotional dysregulation and service related difficulties (e.g. disengaging, frequently calling services). At the time of interview, all participants had completed at least one cycle of DBT group skills training, in line with the inclusion criteria. However, there were some variations in the stage of therapy participants were at; some had completed treatment, others had previously completed treatment and were currently receiving additional 1-1 sessions, and others were still currently attending the complete DBT programme.

Table 9. Participant demographics

Pseudonym	Age	Sex	Ethnicity	ID	Diagnoses	Reason referred for DBT	Cycles of DBT	Stage of treatment
Evelyn	43	Female	White British	Mild	BPD	Self-harm behaviours, suicide attempts, emotional dysregulation	2 cycles	Completed October 2017
Tess	40	Female	White British	Mild	BPD	Self-harm behaviours, suicide attempts, emotional dysregulation	2 cycles	Completed February 2017
Katherine	37	Female	White British	Mild	BPD	Self-harm behaviours, service disengagement	2 cycles	Completed February 2018
Harry	26	Male	White British	Moderate	Characteristics of BPD	Suicide attempts, emotional dysregulation	1 cycle	Currently engaged in treatment
David	52	Male	White British	Mild	BPD	Self-harm behaviours, suicide attempts, aggression, emotional dysregulation	1 cycle	Currently engaged in treatment

Pseudonym	Age	Sex	Ethnicity	LD	Diagnoses	Reason referred for DBT	Cycles of DBT	Stage of treatment
Sandra	45	Female	White British	Mild	Characteristics of BPD	Suicide attempts, aggressive behaviour, calling emergency services	1 cycle	Currently engaged in treatment
Roger	27	Male	White British	Mild	Characteristics of BPD	Self-harming behaviours	1 cycle	Currently engaged in treatment
Helen	26	Female	White British	Mild	Characteristics of BPD	Self-harming behaviours, emotional dysregulation	1 cycle	Currently engaged in treatment
Emily	43	Female	White British	Mild	BPD	Severe emotional dysregulation, aggressive behaviours	1 cycle	Currently engaged in treatment
Barbara	43	Female	White British	Mild	Depressive illness	Emotional dysregulation	2 cycles	Completed December 2015. Currently receiving 1-1 therapy
Carole	37	Female	White British	Mild	BPD, autistic features	Emotional dysregulation	2 cycles	Completed December 2015. Currently receiving 1-1 therapy

Procedure

Ethical approval

The research was granted ethical approval by an NHS Research Ethics Committee (Appendix 4) and by the Research and Development Department of the two NHS Trusts (Appendix 5 & 6).

Recruitment

Individuals who met the inclusion criteria were approached by a clinician known to them about the study. Those who were interested in the research were provided with an information sheet (Appendix 7), which the clinician supported them to read through. There was a minimum of 24-hours between being given the information sheet and taking part in the interview.

Information sheet

Standard information sheets can have large amounts of written text, which may be difficult for individuals with ID to read and understand. Guidance regarding how to develop written materials which are easier to understand was therefore taken from the Department of Health (2010). Key adaptions included the use of pictures, larger font, shorter and simpler sentences (which sound natural when spoken).

Informed consent

When conducting research with people with ID, it is important that researchers take steps to assess the individuals' capacity to make an informed decision about taking part, *prior* to doing so (Arscott, Dagnan & Stenfert-Kroese, 1998). The researcher

therefore asked participants some ‘comprehension questions’ prior to the interview, to ensure that they had fully understood what the research involved and what their rights were. All participants’ responses suggested that they were able to consent to being interviewed. Participants were then supported to read and sign the consent form, which had also been adapted to be more accessible (Appendix 8).

Data collection

A semi-structured interview schedule was developed through discussions within the research team (Appendix 9); interview questions were also informed by the interview schedule of a similar study (Roscoe et al., 2016). IPA advocates the use of open questions, where participants are encouraged to talk at length (Smith et al. 2009), however, some individuals with ID may struggle to respond to open questions and provide reflections (Holloway, 2005). The interview schedule was therefore used flexibly, with the researcher paying close attention to the participants’ responses, adapting the style of questions and prompts accordingly, to support the individuals to provide a detailed account of their experiences.

Participants were interviewed in a private room at the service where they received DBT. One participant chose to have their DBT therapist present for the interview, whilst the other participants were interviewed by themselves. Interviews were audio-recorded and were between 23 and 48 minutes in length (mean= 38).

Data analysis

Interviews were transcribed verbatim, identifying information was removed and participants were assigned a pseudonym. The IPA process of analysis was carried out using the 6 steps described by Smith et al. (2009) (Table 10).

Table 10. The steps of carrying out IPA

Step	Description
Step 1: Reading and re-reading	This step involves immersing oneself in the data and entering the participants' world by reading and re-reading the first written transcript. Listening to the audio recording also helps to keep the participants' voice in mind when re-reading the transcript. Initial striking observations and recollections from the interview were noted, so that the researcher could bracket them off at this stage and remain focused on becoming immersed in the data.
Step 2: Initial noting	This step involves developing detailed notes and exploratory comments for each line of the data. Comments can be descriptive (i.e. focusing on the content of what has been said), linguistic (i.e. focusing on the specific language use of the participant) and conceptual (i.e. becoming more interpretative) in nature.
Step 3: Developing emergent themes	This step involves developing emergent themes based on the exploratory comments and initial notes from step 2. Themes reflect the participants' initial descriptions and also the analysist's interpretations.
Step 4: Searching for connections across emergent themes	This step involves drawing together the emergent themes and forming clusters of related themes. The analyst attempts to recognise the interesting and important features of the participants' narrative.
Step 5: Moving to the next case	This involves repeating the above process for the next participants' transcript. Each participants' transcript should be analysed separately, with focus on the individuality of each participants' account, in line with the idiographic commitment of IPA. This means ideas and themes emerging from previous transcripts should be bracketed off as much as possible, allowing new themes to emerge with each transcript.
Step 6: Looking for patterns across cases	This final stage involves looking for patterns and connections across the transcripts. Themes are often reconfigured and relabelled as part of this in order to form 'superordinate themes'. The analyst attempts to recognise themes which are particular to an individual and shared higher order concepts.

In order to aid transparency, as advocated by Yardley (2000), Appendix 10 provides an excerpt from a transcript with exploratory comments and emerging themes. Smith (2011) argues that good quality IPA papers indicate how prevalence of a theme is determined; recurrent themes across transcripts were classified as 'superordinate themes' if they were present in at least half of the participant interviews (Appendix 11).

Quality and validity

During the data collection stage, the researcher sought supervisory feedback about the quality of the interviewing. This enabled adaptions to be made within subsequent interviews, to ensure that the researcher was noticing cues from participants and paying attention to their individual experience (Smith et al. 2009). Engaging in this process demonstrates commitment and rigour, as described by Yardley (2000).

During the data analysis stage, the researcher engaged in credibility-checking of the initial notes and emerging themes through the use of supervision and the attendance of IPA peer group meetings. In order to further increase the plausibility, credibility and validity of the interpretations, the superordinate themes and accompanying subthemes were reviewed by clinicians independent of the study, who have experience of IPA.

Reflexivity

A reflexive journal was kept throughout the research process in order to capture and reflect on my perceptions and experiences (Larkin & Thompson, 2012). This helped

to notice initial thoughts and feelings regarding participants' narratives, whilst also recognising how my beliefs and previous experiences may have impacted on how I conducted the interviews and the interpreted the data. It was hoped that engaging in this process would reduce the presence of researcher bias. I have previous experience of working with adults and children with ID and I feel very passionate about these individuals feeling heard and empowered. I noticed that I often viewed narratives through this lens and interpreted experiences in relation to the sense of power individuals perceived they had. Making use of supervision, the IPA group meetings and the independent reviewers therefore enabled me to check the plausibility of the interpretations I was making.

Similarly, during the interview process, I noticed how eager I was to support individuals to tell their story and ensure that their voices were heard. This resulted in me developing a range of potential prompts for questions in order to facilitate this dialogue. As interviews progressed, I recognised the assumptions I had been making about how capable the participants were going to be, often underestimating their articulateness. Whilst it is important to consider what potential adaptions may need to be made prior to interviewing people with ID, I became more aware of how important it is to simply see each person as an individual and respond to them appropriately.

Results

Four super-ordinate themes and nine corresponding subordinate themes emerged during the analysis and are represented in table 11. These themes capture the individuals lived experience of DBT and the impact this had on their lives.

Table 11. Superordinate and subordinate themes

Superordinate theme	Subordinate theme
Experience of power	a) Having a voice in therapy b) A shifting position of power
Differences in therapy contexts	a) Openness and filtering b) Seriousness and playfulness c) Being in a group as challenging d) Being part of a group as rewarding
The experience of a positive therapeutic relationship	
A new way of being	a) Integrating DBT into life b) Change c) A shifting sense of self: old me and new me

Theme I– Experience of power

There was a strong narrative regarding the experience of power throughout the majority of interviews. Whilst some participants spoke about power more explicitly, for others, this was more implicit in their accounts. The experience of power is represented here as a distinct theme, however elements of power run within other themes also.

a) Having a voice in therapy

A number of participants' accounts suggested that during DBT they made efforts to actively express their needs and subsequently get these needs met. For instance, when individuals found new concepts/skills difficult to understand, they appeared to take control of the situation and assert themselves:

> *…I said "what we will have to do is try and explain it to me again". So they explained it to me again in more detail but slowly for me (Barbara)*

By Barbara voicing what she needed, therapists were able to responsively adapt the content and delivery of the information described. Individuals seemed to become more confident in not only asking for information to be explained again, but for it to be explained at a more appropriate level:

> *…if there is anything that you don't understand (…) now we are so upfront, we will just say to them, "can you talk in English please?" (laughs) (Emily)*

Emily's account suggests that over time, individuals were able to openly and humorously, use their voice to communicate difficulties in understanding.

Most individuals displayed a sense of taking ownership and responsibility for their own learning; participants were not passive recipients of information, but instead were proactive agents in their learning. In the following exchange, Tess describes how she actively sought opportunities to be involved during sessions and she shows awareness of what helps her to learn most effectively:

> *Tess: …I got up and done all the drawings on the whiteboard (...) And the writing on the whiteboard (...) I asked if I could get up and do some writing*
>
> *Interviewer: What made you want to do the writing and the drawing?*
>
> *Tess: …Listen more better if I'm doodling or writing words down (Tess)*

Comparatively, Barbara seemed to use her voice in therapy to not only aid her own learning, but to also speak on behalf of the group when she felt things were

inequitable. Barbara appeared to be seeking an equal sense of power and establish balanced expectations for the staff and service-users in this example:

> *…I said "well if we've got to do homework, then the staff's got to do their homework" (…) So every week, I bought my homework in, the staff bought theirs in (…) We ain't going to do it if they ain't going to do it, it's not fair (Barbara)*

By exerting control in this situation, Barbara became an active agent of change in the way her group operated.

b) A shifting position of power

Individuals seemed to view DBT as being a learning environment where they acquired new knowledge/skills. They appeared to experience learning within DBT as a *process,* which involved moving through different stages. Their narratives suggest that within this learning process, they experienced a shift towards being in a more powerful position.

When starting the programme, most individuals took on the role of a learner and placed themselves in a learning position; comparatively, they put the therapists in the role of teachers- arguably a more powerful position.

> *…it's a course that you go on to get help in learning about feelings, coping in a difficult situation and that sort of stuff (Helen)*

> *[the therapists] teach us, teach us how to like cope (Emily)*

> *They taught us a lot of things (Harry)*

Some participants showed conscious awareness of the lack of knowledge and/or adaptive coping skills they previously possessed:

> *So all my emotions… I didn't know what they were for (Emily)*

…if I was having a crisis, I would just shout and self-harm… because I did not know how to cope with it (Evelyn)

I didn't know how to open up, I didn't know how to kind of express my feelings without kind of like going off on one, like overpowering myself (Roger)

Many recognised that there was a *need* to learn new skills in order to help them to manage better:

I needed to know what skills I needed… and for other bits and pieces like my emotions... to sort them out... (Barbara)

Because I need[ed] help and that with things… like learning skills (Carole)

Participants spoke about initially struggling to make sense of new information/skills, then moving towards a greater understanding. They appeared to move from a position of 'not knowing' to a more powerful position of 'knowing'. Moving to a 'knowing' position was a gradual process for most participants; David and Katherine both highlight the element of time involved in this process:

At first, pretty hard… but… as time went on… they got pretty easy (David)

When I first got told it, no I wasn't sure about it... but I think over time … I started to get used to it (Katherine)

In contrast, Barbara and Roger experienced the shift towards 'knowing' as more of a sudden 'eureka' moment:

…I kind of went "whoa, I understand this more clearly now" (Roger)

…all of a sudden it will just hit me, and I think "whoa I've got it now" (Barbara)

Some participants spoke about achieving mastery over the skills/ideas they had learnt. There was a real sense of accomplishment and pride around this:

All my skills I've learnt I've now got mastered… I've got all the skills I needed to learn mastered (Barbara)

Several participants appeared to go a stage further in the learning process and move from being a learner to a teacher:

> *…you learn how to deal with yourself in crisis and how to deal with your emotions. I'm teaching everybody else, like my staff, you know "you can't say that, you've got to do this… you can only do it one thing at a time". And they are saying "I can't do it" and I say, "there is no such word as can't" (Tess)*

Tess seemed to have taken on a mentoring role, whereby she was not only applying the knowledge she had gained herself, but also using it to empower and motivate others. David also described the *'ego boost'* he experienced at being able to *'teach'* and help others, through *'passing the knowledge on'.*

It seemed apparent across individuals accounts, that the acquisition of knowledge/skills was perceived as highly valuable; moreover, feeling more knowledgeable/skilled appeared to be particularly associated with feeling more powerful:

> *I had basically more knowledge than the DBT session itself (Roger)*

This may suggest that whilst gaining knowledge/skills is arguably beneficial in itself, for these individuals, it had a further impact of providing an increased sense of power.

Theme II- Differences in therapy contexts

The way therapy was constructed (i.e. individual therapy, group), appeared to affect participants' experiences. This theme captures how individuals experienced DBT across the different therapeutic modalities.

a) Openness and filtering

There was a strong narrative around the value participants placed on being able to talk openly and honestly. Individuals claimed that they were able to be '*more'* open/honest and found it '*easier to talk'* in a one-to-one setting, compared to when they were in the group. A number of individuals actively spoke about *'preferring'* individual therapy as a result.

For some individuals, the presence of others hindered their ability to talk openly/honestly, moreover they seemed conscious of other group members *'listening in':*

> *Being honest, it's good (…) whereas if you are in the group you can't [be] (…) Because you've got… loads listening haven't you (Carole)*

Participants described being able to *'talk about anything'* in individual therapy; they experienced no limitations or boundaries around what could be discussed. Comparatively, they seemed to filter what they said in the group and showed greater awareness of boundaries. Moreover, they considered the impact of what they said on other group members:

> *In one-to-one's you can talk about everything, like from back to when you were a child, to present... everything that's gone on in your life… but not like in the [group] sessions because you might upset someone else (Emily)*

> *One-to-one's you could talk... group skills you can't talk about your personal life... because you might upset other members and if they talk about it, they might upset me (Katherine)*

Participants clearly differentiated between what could be spoken about in the different contexts; there was a sense that individuals had internalised rules and recognised the importance of adhering to them.

Whilst the rationale for filtering information and the subsequent mutual respect demonstrated was evident, it was apparent that significant value was placed on being able to talk without any restriction:

> *David: You have to be conservative with the group, because with a group, they can take offence. With [the therapist], she can sit you down and say "there's only two of us in here, get it off your chest". And by heck do I get it off my chest…*
>
> *Interviewer: Ok so what did you like most about the one-to-one's?*
>
> *David: …the freedom of the speech (David)*

As we can see from this exchange, David adapted the way he behaved in the group, so comparatively, being able to express himself freely in a one-to-one context seemed to be experienced as liberating for him.

b) Seriousness and playfulness

The different therapy contexts appeared to meet different needs and serve different functions for the participants; this impacted on how the participants presented themselves, the emotions they experienced and how they made use of the sessions. Tess described presenting a different version/part of herself when in a group setting, compared to when she was in a one-to-one setting:

> *…I suppose it was two hats. One was the serious hat and one was the one that you could muck around in (Tess)*

Many echoed this and described being more *'serious'* when working individually and being more playful in the group. Participants described *'talking about more serious stuff'* in individual therapy, including exploring and reflecting on current struggles and previous difficult life events. Most experienced the content of sessions as somewhat intensive and thought provoking:

…you have got to think a bit in that hour (Harry)

For some clients, the nature of the sessions elicited uncomfortable feelings and emotional expression:

…it was just upsetting… really upsetting (Katherine)

…there were some sessions that I came out crying, I came out worse than before I came in (Roger)

For Roger, it seemed that expressing his emotions through crying during/following sessions had been a detrimental experience for him. Comparatively, other participants described emotional expression in sessions as a positive experience and there was a sense of relief associated with this:

… we have talked about my emotions, I've even cried in front of her… I just could not hold it in no more… I said "oh sod it", and my emotions come. I let go of my emotions… It felt a weight lift off me (David)

In contrast to individual therapy, participants described the group as somewhere they could be playful and have fun:

It was fun (Tess)

It was fun, we had a laugh (Carole)

They spoke positively about the engaging, enjoyable activities and games they were involved in as part of the group:

There's lots of fun activities… which are interesting (Helen)

I liked a lot of the group… the games we used to play in there, we used to play different kinds of games (Barbara)

Individuals seemed to appreciate the emphasis that was placed on maintaining a light-hearted environment and the use of practical activities to facilitate learning. It appeared important that individuals had the opportunity to be playful within DBT due to other components of the programme being experienced as more intensive.

c) *Being in a group as challenging*

The majority of participants spoke about challenges associated with the group component of DBT. Most individuals highlighted social challenges, in particular, difficulties with meeting new people:

> *I'm not really a new people person. I don't really like talking to new people because it makes me feel anxious… It's alright when you know them but not when you don't (Helen)*

Helen's perception of herself seemed to contribute to the experience of starting group sessions as being particularly difficult. Feelings of anxiety when talking to new people was a shared experience by many and individuals seemed to find comfort in established relationships.

Participants described a period of adjustment in relation to being with new people in a group setting. In the following exchange, Evelyn highlights the importance of time in helping her confidence develop:

> *Evelyn: At first difficult… Really really difficult… but as it went on I got more and more confident I think*
>
> *Interviewer: So what helped you to become more confident?*
>
> *Evelyn: I think it was just time (Evelyn)*

There was a sense that Evelyn really struggled initially, in her narrative she also spoke about not wanting to *'join in for the first few sessions'* and taking a while to *'settle in'.*

Many participants were fearful of judgement from others in the group and this appeared to hinder their willingness to engage in the group activities.

> *…the staff was doing the role play bit and they expected us to do it. And I thought "I'm not going to make a fool of myself" (Barbara)*

Barbara appeared to avoid performance-based tasks, which seemed to be linked to a fear of ridicule or embarrassment.

Individuals narratives were predominantly related to feelings of *anxiety* within the group context, however, some individuals experienced other dominant feelings such as *frustration* towards others:

> *…I get distracted so easily… there would just always be something that would stop the flow of what was going on… someone kicking off… someone getting upset… (Evelyn)*

Evelyn seemed to experience the presence of others as distracting, moreover she appeared to view their behaviours as detracting from her therapy experience. Perhaps conversely, the *lack of* others presence was felt by David as a significant loss:

> *…they've got such a good crowd in at the moment and I hope nobody else… gives up… it's a bit of disappointment… because you get used to them (David)*

David's narrative suggests that he was able to build relationships within his group and therefore when group members dropped out of treatment, this was difficult for him.

d) Being part of a group as rewarding

Whilst participants spoke at length about the challenges of being in a group setting, they also strongly recognised the value of being part of a group. The group component appeared to meet certain needs that the individual sessions were less able to.

The group served a social function for many, providing opportunities to interact and develop relationships. Sandra in particular spoke about how she was able to *'meet new friends',* and this was echoed by others:

> *I'd never make new friends and coming to the group has made me do that… And that's built my confidence up, meeting new friends (Barbara)*

Barbara appeared to directly associate coming to the group, with making new friends and a subsequent increase in confidence. It seemed that having an increased social network was a novel experience for most participants.

Participants seemed to gain a sense of belonging and connectedness from attending the group; particularly benefitting from interacting with others whom they identified with:

> *Interviewer: …what would you say you liked most about it?*
>
> *Harry: Being with other people living with the same mental health (Harry)*

The above exchange highlights how significant it was for Harry to be with others whom he felt similar to. Similarly, Tess described feeling less alone knowing that others shared her struggles:

> *…people were all in the same boat… I'm not on my own. There are other people out there who are struggling (Tess)*

Individuals could relate to one another and seemed to find strength and unity from this. Interestingly, participants seemed to develop a group identity and there was a sense that they felt they were part of a special group:

> *…the good thing is that whatever we say in the group, stays in the group, that is one of our group rules. And like things like social media, some of us are friends on Facebook, but we never discuss what went on. Like today for instance, we don't discuss what went on in that room, it doesn't go anywhere else than that room (Emily)*

> *…everything in the group has got to be kept in the group, you can't tell anybody outside the group, so I never did, I never discussed anything with the group outside the group (Barbara)*

The way Emily spoke about the group created feelings of intrigue and curiosity around '*what went on'.* There seemed to be a shared agreement around the *'rules'* of the group and what was expected of its members. Similarly, the extract from Barbara emphasised this sense of being part of an in-group, whereby nobody outside of the group could be privy to what was discussed. Whilst individuals could simply be adhering rigidly to confidentiality, their narratives seemed to go beyond this and suggested that being part of a group, particularly one which could not be accessed by anyone, made them feel special and created a strong sense of belonging.

Theme III- The experience of a positive therapeutic relationship

A theme which emerged throughout the majority of narratives, related to the positive therapeutic relationship experienced. Individuals spoke at length about the various qualities and attitudes of the therapist which contributed to the development of this positive relationship.

Several individuals described feeling listened to and heard by the therapist, and there was sense of feeling genuinely understood. For Katherine, it seemed more evident to her that her therapist was *really* listening and understanding her, in comparison to her previous experiences of therapists:

> *This time my therapists listened to me (…) just listening to me, much clearer and understooded much better (Katherine)*

There was a sense of relief from Evelyn that she had finally been able to express herself authentically to another and feel understood:

> *I felt like for the first time in a very long time, I can properly say how I feel, and somebody gets it (Evelyn)*

A number of individuals spoke about feeling able to trust the therapist. For Tess, trusting the therapist, being listened to and understood were all intrinsically linked:

> *Tess: I can trust [the therapist]*
>
> *Interviewer: (…) So what did [the therapist] do that made you feel you could trust her?*
>
> *Tess: Listened. She understood (Tess)*

Feeling able to trust another person felt particularly significant for a number of individuals, who drew on difficult past relational experiences.

Emily seemed to show awareness around the potential for an imbalance of power within the therapeutic relationship. She noted how the therapists made efforts to minimise this, interacting with service-users respectfully, as their equals:

> *They don't treat us like children, they treat us like adults. Like they don't talk down to you, they are on your level (Emily)*

Participants viewed the therapist as being flexible and adaptable in sessions, in that the therapist was led by the client, so their wants and needs were at the heart of how the session was conducted:

> *[the therapist] would play it by ear, depending on what I wanted to talk about and what I didn't want to talk about (Tess)*

Individuals felt that the therapist was attuned to them and responded appropriately to their cues:

> *…It's like she knows if you're sad, she knows if you just want to sit there and be quiet, she'll just sit there and be quiet (Emily)*

Participants experienced the therapist as being validating, accepting in their approach and they were perceived as having a non-judgmental attitude:

> *…she doesn't judge what you say and that's where it works (David)*

For David, there seemed to be a clear link for him between the therapist's non-judgmental attitude and how effective their relationship was.

Individuals experienced therapists as being available and accessible to them, which created feelings of safety. Several participants likened this to having a *'security blanket'*. They seemed to take comfort in knowing that the therapist would reliably and consistently be there, should they need support:

> *…she's always here for me if I need her (Barbara)*

> *…I can phone [the therapist] every time I get uptight right, and talk to her (Sandra)*

Whilst most participants experienced a positive therapeutic relationship, conversely, Roger felt that he *'couldn't get what [he] needed'* from his therapists. Roger appeared to place more value on the relationship and interactions he had with someone with lived experience of DBT:

> *…if you put a person who's already experienced it and a person who is going through it, it helps the person who is going through it (Roger)*

Roger considered his DBT experience to be *'vastly greater'* as a result of drawing on the lived experiences of an ex-service user.

Theme IV- A new way of being

This theme captures the impact DBT had on participants' lives. Individuals were able to implement the skills they had learnt and noticed numerous changes, not only in their everyday lives, but also in their sense of who they are as people.

a) Integrating DBT into life

Participants described being able to take the skills/knowledge that they had learnt in DBT, generalise these to other settings and integrate them into their day-to-day lives:

> *I did like a sensory table, when I got candles and a lava lamp and other stuff… because in the group I learnt that if you have something to focus on, it takes your mind off what you are thinking about. So I set that up… and when we used to go for walks we used to notice stuff... so if I'm out and about I notice stuff more now, which helps. (Evelyn)*

Evelyn seemed to have drawn on particular DBT ideas which were most useful/ relevant to her and was implementing these outside of sessions. Participants commonly referred to utilising mindfulness-based exercises in their narratives. Individuals seemed to have adopted a mindful way of being when completing everyday activities:

> *…you know like when you have a drink, like tasting... like when I have a hot chocolate, now before I drink it, I have a smell of it and that. It's good… And when I'm eating, like taste what you are eating (Carole)*

The DBT ethos and exercises seemed to have become a part of life for most participants and arguably a 'new norm':

> *I used to struggle doing it, but now I just do it, it's like a normal routine to me, it's like making a cup of coffee, it's just normal routine now (Barbara)*

This excerpt suggests that Barbara experienced a shift from initially struggling, to integrating DBT into her life and simply seeing it as a *'normal routine'* now. For some

individuals, the application of DBT skills/ideas appeared to have become an unconscious process:

> *[the therapist] said "you are doing it every day… and you don't realise you are doing it" (Emily)*

This may indicate that DBT had become such a natural part of Emily's life, that she was applying ideas/skills automatically and habitually, without conscious awareness. It is important to note that several participants described the benefits of involving others (i.e. support workers, family) when generalising their skills. Individuals noted that others could *'understand more'* and subsequently '*help me a bit better'* when they had a greater awareness of DBT.

b) Change

Participants described the various changes they had experienced following attending the DBT programme. This included emotional, behavioural, cognitive and interpersonal changes, as well as greater feelings of empowerment.

In relation to emotional change, many participants noticed that they were not experiencing difficult emotions such as anger as intensely or frequently, and described feeling significantly calmer:

> *I've noticed I'm a lot calmer… I'm not losing it every 5 minutes (Sandra)*
>
> *I am a lot calmer (Emily)*
>
> *I don't get angry so much now (Evelyn)*

Some participants described developing a better understanding of emotions generally. Emily's narrative particularly, suggested that she experienced greater *acceptance* of her emotions:

> …I have learnt since coming here, that it is ok. Like its ok to be sad, its ok to be cross (Emily)
>
> …it's alright to be angry sometimes. It's alright to be cross, it's alright to be upset, it's alright to be sad (Emily)

Similarly, David appeared to have given himself permission to genuinely experience and express a wider range of emotions:

> *Interviewer: And what's changed then, from then until now?*
>
> *David: (…) I can absolutely laugh and not feel ashamed of laughing (…) And… it's alright to cry and not be judged (David)*

Participants also spoke about behavioural changes they had noticed. Some noted that they were engaging in fewer risk behaviours following DBT:

> *I'm not self-harming now... That's a big step for me… Because I used to do it all the time when I got angry, but now I've realised it doesn't make life any easier by doing that, it just makes it worse (Helen)*

Helen emphasised the personal significance of this change for her. She seemed to have come to a powerful realisation and recognised the negative impact self-harming was having on her life. Similarly, Carole's perception of how well she was coping, seemed to be intrinsically linked to the absence or presence of risk behaviours:

> *I am doing well yeah…I haven't done bad things… Like I haven't done bad behaviours like overdosed or anything like that (Carole)*

Individuals described utilising alternative, adaptive coping strategies to manage difficult situations and emotions. For Emily, there seemed to be a sense of pride around the volume of newly acquired strategies she had:

> *I've got all the things that will help me when I'm upset or like in a crisis. Like I've got phone [the therapist], speak to my 1-1 support worker, listening to chimes, giving my guinea pig a cuddle, relaxing in the bath, a cup of tea, my self-sooth box and going for a walk (Emily)*

Emily's ability to list numerous coping strategies may suggest that she felt she had a lot of choices and options available to her now.

Some participants noticed a change in their thinking styles and the way they perceived situations. Evelyn gave an example of when she was able to see a situation more rationally and think more flexibly:

> *…if... I send someone a text and they don't text back… I don't take it personally. I'm just like maybe they haven't got credit… maybe their battery has run out… maybe they haven't got a signal. It's just stuff like that now. I think I've noticed that more. (Evelyn)*

Evelyn noticed that she is now more skilled in interpreting situations in a more balanced way and can establish alternative thoughts or explanations for difficult scenarios, which would have previously caused her distress.

Similarly, Roger described difficult situations where he has now *'thought about it differently'* compared to how he would have previously made sense of the situation; he also noted that he now gives more thought to how he could *'approach the situation differently'.*

Participants described a number of interpersonal changes they had observed following DBT. Many individuals noticed positive changes in their existing familial relationships:

> ***…****before I started doing this, like my relationship with like my Mum and my dad was not good, because I was always angry, always cross, and now, its lovely. (Emily)*

Emily attributed the previous difficulties in her parental relationship to her persistent anger and aggression. It seemed that by developing skills in managing emotions, this impacted on her interpersonal relationships. Similarly, Helen described a reduction in confrontational interactions with her Mum:

> *Less arguing with my Mum, which we used to do all the time, but we've stopped doing that now so, we just talk… Instead of arguing. So that's better now… (Helen)*

The communication style between Helen and her Mum seemed to have shifted away from being argumentative towards something mutually respectful, which Helen recognised as being more effective. Tess also seemed to adapt her communication style following DBT and demonstrated assertiveness in her interactions:

> *…when Mum tells me to do more than one thing, I tell her now that "I can only do one thing at a time. I can't wash up, do the dishwasher and make the tea at the same time. I have to do one thing at a time". (Tess)*

Tess appeared to have developed the ability to articulate her needs and limitations to others when demands were placed on her.

Other individuals noticed changes in the development of *new* relationships. Participants described a previous lack of social support and difficulties with making friends, however this appeared to have changed:

> *…it don't take me long to make new friends now like I used to, because I never used to have many, but now I've only got to go out and they say "do you fancy a…" and then we are out, having a laugh and a joke (Barbara)*

Barbara spoke about the ease with which she can now make new friends, which was a stark contrast to her experiences prior to DBT. Both Barbara and David also spoke about being *approached* by others now:

> *Where they would stay clear of me, [now] they are coming over and talking to me (David)*

Similarly, this was a polarised experience for David, as he previously spoke about others avoiding him due to aggressive behaviours.

Some participants made reference to feelings of empowerment following DBT. Katherine reflected on what she had learnt in DBT, particularly in the context of the difficult previous life events she had experienced:

> *…showed me… part what I put up with, and part what I wouldn't put up with and showed me… I got strength to do something about it instead of leaving it and I won't put up with it anymore (Katherine)*

Katherine appeared to have found inner strength, where she felt more able to take control of her life and place herself in an empowered position rather than the submissive position she was previously in. Similarly, David spoke about the difficult upbringing he experienced, where the negative messages he repeatedly received from others appeared deeply ingrained. He reflected on what he had taken from DBT:

> *…I was bought up "be seen and not heard"… you're constantly told "get over there", "talk when you're talked to, otherwise be quiet"… DBT has taught me that I have got a voice (David)*

Through DBT, David appeared to have challenged the invalidating messages he was exposed to frequently whilst growing up, which served to diminish his opportunity to be heard. The empowering, validating environment provided by DBT helped David to finally have a voice.

c) A changing sense of self: 'old me' and 'new me'

The various changes participants experienced, seemed to impact on their sense of self and who they are as individuals. Many referred to how they *used* to be as a person and the behaviours they used to exhibit (i.e. 'old me'); they also spoke about how they are now and the 'new' person they have become.

In relation to how they used to be, individuals predominantly spoke about previous aggressive feelings they experienced and dysfunctional behaviours they displayed:

> *I used to kick doors and punch a hole in them (Sandra)*
>
> *I would have screamed… and just been really angry (Helen)*
>
> *…before I used to smack the walls and smack doors and put holes in walls in my temper... (Emily)*
>
> *I kept being angry all the time, I kept having a go at people (Roger)*

There was a sense of feeling out of control, overwhelmed and frustrated with how things were. Participants previous sense of self appeared to be formed by the angry emotions and behaviours they experienced. In Emily's narrative, she referred to herself as *'that horrible person'* and spoke about *'that angry person that I used to be'.* Emily seemed to experience a shift away from identifying as that '*angry'* and *'horrible'* self, and moved towards seeing herself as '*this nice, calm person'.* She spoke explicitly about how significantly her sense of self had changed:

> *I'm a totally different person to what I was… totally different person (Emily)*

Similarly, David's sense of self was also previously made up of being an *'angry person':*

> *I was an angry person, you wouldn't talk to me. You certainly wouldn't be in here one-to-one. That's how bad I was. (David)*

This extract seemed to imply that David's anger impacted on how willing others were to interact with him, perhaps due to fear around his potential unpredictability; something previously alluded to. Interestingly, David spoke about how others around him also noticed a change in him as a person following DBT:

> *He goes "you're a different person. I don't know what you're doing, or where you are getting your personality from lately, but it's a good thing" (David)*

Hearing this from another person felt particularly important for David and seemed to reinforce the changes he had made.

For Barbara, the shift she noticed within herself seemed somewhat different. There was a sense that she previously saw herself as a fiercely strong, independent woman and therefore asking for help from others was a challenge to her identity:

> *I've never asked for help, I've always done it myself… so when people [said] to me "are you ok?" I [said] "yeah" and "I don't need nothing because I am my own woman and I do it myself" (Barbara)*

During DBT, Barbara appeared to grow more comfortable with help seeking and accepting support from those around her. This shift was reflected in her narrative:

> *…but I'm finding asking people for help was a big relief because I've never done it' (Barbara)*

It was evident that Barbara experienced a strong sense of relief when she allowed herself to ask for help. It is possible that in line with a dialectic philosophy, her sense of self evolved to incorporate and synthesise the potentially opposing ideas of *independence* and *asking others for help*.

Discussion

This study aimed to explore individuals with ID experiences of DBT in a community setting; the analysis identified four main themes. Theme I captured nuanced accounts about the experience of power in DBT, whereby individuals described having a voice in therapy and appeared to experience a shift in their sense of power. Theme II highlighted how participants made sense of the different therapeutic contexts, how these modalities met different needs and the associated challenges/rewards experienced. Theme III focused on the positive therapeutic relationship experienced by participants. Theme IV identified the impact of DBT had on participants everyday lives, moreover their changing sense of self.

The concept of 'power' emerged throughout various narratives and across themes. Theme I highlighted that the empowering and validating environment created within DBT, appeared to facilitate individuals *having a voice* in sessions, as individuals described asserting their needs, exerting control and showing agency around their learning. This suggests that they were 'active participants' rather than 'passive recipients' in therapy, which challenges previous perceptions about this populations ability to make use of or meaningfully take part in therapy (Handley, Southwell & Steel, 2012). As individuals with ID often experience a lack of choice or control in their day-to-day lives (Finlay, Walton, & Antaki, 2008), becoming skilled in using their voices both within and outside of therapy feels particularly important.

Having the opportunity to learn new relevant skills has been associated with feelings of personal growth and empowerment for people with ID (Atkinson, Dearden &

Dunne, 2015). The findings from this research support this notion, as participants seemed to value the skills/knowledge acquired through DBT and this appeared to be associated with a sense of empowerment. Participants seemed to experience a shift in their position of power, as part of the process of learning; they appeared to move from the arguably more subordinate position of a learner, towards mastery, and the role of a teacher. Individuals spoke with pride about the skills/knowledge they had been able to master; this echoes the findings by MacMahon et al. (2015) where individuals with ID were interviewed following attending a CBT-based group and were eager to share their expertise and sense of mastery. Experiential claims around taking on a teaching role, echoed the findings of Thomson and Johnson (2017), who highlighted that clients wanted to teach staff and peers on the ward about DBT.

The 'conscious competence' model of learning postulates that when learning a new skill, we progress through four stages: *unconscious incompetence* (we are unaware of what we do not know), *conscious incompetence* (we become aware of what we do not know but are unable to demonstrate the skill effectively), *conscious competence* (we are now competent in the skill, but it requires effort) and *unconscious competence* (we have mastered the skill, can carry it out as 'second nature' and may then teach others) (Adams, 2016). This model appears to reflect the learning process reported by participants, as they described awareness of the skills/knowledge they were lacking (*conscious incompetence*), then described developing greater knowledge/skills (*conscious competence*) and finally, achieved mastery, used the skills habitually and were able to teach others (*unconscious competence*).

Theme II highlighted the differences participants experienced in therapeutic contexts. Thomson and Johnson (2017) similarly found that participants differentiated between the one-to-one and group modality, with individuals recognising the different functions of these therapeutic settings and what was expected of them. Participants emphasised the unique and valuable element of the one-to-one interactions, whereby they could talk privately and openly. This is consistent with other literature, which found that individuals with ID experienced being able to talk in therapy as helpful (Merriman & Beail, 2009; Pert et al., 2013). However, these findings go beyond that, and emphasise that individuals highly valued the absence of boundaries and limitations of what could be spoken about within a one-to-one context.

In relation to the group context, participants experiences were somewhat in line with Social Identity Theory (Tajfel & Turner, 1979), in that they appeared to feel part of a special collective or 'in-group', whereby individuals outside of the group were not permitted to know what was discussed within it. It seemed that being with others who had similar difficulties and shared struggles provided a sense of belonging for participants. Being in a group setting also provided social opportunities and the development of friendships. The group component of DBT may therefore be particularly important for this population, who often have limited social support (Lippold & Burns, 2009).

Theme III highlighted that participants experienced a positive therapeutic relationship, where the relationship was characterised by trust, validation, attunement, availability, empowerment and a non-judgmental stance. Similarly,

Roscoe et al. (2016) highlighted that the therapeutic relationship appeared to influence participants engagement in DBT. In the wider literature, the therapeutic relationship has repeatedly been associated with positive therapeutic outcomes, irrespective of the model of therapy being delivered (Ardito & Rabellino, 2011). Rogerian principles of empathy, unconditional positive regard and congruence/genuineness are considered to be central to the therapeutic alliance and effective therapy (Overholser, 2007). Individuals with ID often have fewer experiences of being genuinely listened to and accepted by others (Pert et al., 2013); this may provide some insight as to why the value of the therapeutic relationship emerged so prominently in the data.

Theme IV highlighted the various changes individuals experienced following DBT. Participants described utilising skilful behaviours and generalising these skills to other settings; these outcomes are in line with some of the 'treatment functions' of DBT (e.g. skill generalisation) (Dimeff & Linehan, 2001). Moreover, many of the changes experienced by participants, such as a decrease in parasuicidal acts, greater regulation of emotions and improved interpersonal effectiveness, are aligned with the aims of DBT (Panos et al., 2014). This provides evidence for the efficacy of DBT with this population.

Participant's narratives also suggested that they experienced a change in their sense of self. They referred to the person they *used* to be and the person they *are* now. This lends itself to the 'old me', 'new me' model developed by Haaven and Coleman (2000) for individuals with ID who have sexually offended. 'Old me' represents the

previous attitudes, feelings and dysfunctional ways of behaving, whilst ‘new me’ reflects a new identity and positive lifestyle (Ward, Polaschek & Beech, 2006).

Many of the themes which emerged in the data, echoed the findings of the meta-ethnography by Little et al. (2017). For instance, being part of a group was experienced as normalising and validating, whilst also challenging at times; the therapeutic relationship was experienced as the context within which change could occur, and participants described a process of skills becoming automatic and a part of their behavioural repertoire. This suggests that individuals with ID experience many of the same therapeutic processes as the wider population receiving DBT.

Critique

This study contributes to the existing evidence base and provides further insight into the lived experiences of people with ID receiving DBT. It also captures valuable information about the therapeutic processes and outcomes of therapy, which may not be measurable on traditional quantitative rating scales.

The study utilised purposive sampling, meaning the sample was reasonably homogenous, in line with IPA recommendations; however, this sampling method may limit the extent to which we can generalise the findings beyond those involved. IPA is however, concerned with the *depth* rather than the *breadth* of the study (Pietkiewicz & Smith, 2012), less importance is therefore placed on being able to generalise the findings.

The literature suggests that individuals with ID may be more likely to acquiesce or be 'eager to please' during interviews; it is therefore possible that participants in this study were more likely to present positive narratives about DBT and were less likely to explore aspects of the therapy which they experienced as challenging, or were less satisfied with (Baxter, 2005; Hollomotz, 2018). The presence of a therapist during one of the interviews may have also further influenced how this particular participant described their experience of DBT. To reduce the likelihood of acquiescent responding, the researcher was mindful of this during the interviews and adapted the style of interviewing (i.e. open-ended questions, use of prompts as needed, paraphrasing, summarising). Moreover, the narratives which emerged suggested that most participants were able to provide accounts which acknowledged both positive and difficult experiences associated with DBT.

It could be argued that the analysis was subjective, as the themes were developed based on the interpretation of the data by the researcher; it is therefore possible that another researcher may have interpreted the data differently. However, the use of a reflexive journal and supervisory discussion throughout the research process, enabled the researcher to recognise when their thoughts, beliefs, previous experiences and assumptions may have been influencing how they conducted the interviews and made sense of the data. A strength of the study was the various credibility checks which were carried out during the analysis. The researcher utilised supervision and IPA peer group meetings; additionally, the themes were also reviewed by clinicians who were independent to the study, thus increasing the plausibility, validity and credibility of the analysis, and minimising potential bias.

However, a limitation was that a credibility check was not conducted with the participants' themselves. It can be difficult to obtain participant validation, particularly when interpretative approaches are used; however, this may have been beneficial and in line with ethical principles (Beail & Williams, 2014; Coons & Watson, 2013).

The richness of the data was variable across interviews; however, all interviews were included in the analysis and quotations from all participants were included in the text, meaning the voice of every participant was heard. Whilst some of the extracts included were short, they arguably still capture the complex stories of the participants. This provides support to the application of IPA with people with ID, as analysis goes beyond what is being said and seeks to make sense of experience at an interpretative level.

Clinical implications and recommendations

Whilst this research did not seek to actively explore mechanisms for change in DBT, the findings provide some insight into these underlying mechanisms. There seemed to be an interplay between factors unique to DBT (e.g. skill acquisition, multi-modal structure) and features common across therapies (e.g. therapeutic relationship). We could therefore argue that being able to communicate openly and without restriction, in the context of a positive, validating, empowering therapeutic relationship, whilst also being able to learn new skills, develop friendships and feel part of a collective, in a more playful group context, facilitated therapeutic change. This highlights the distinct contributions the different therapeutic modalities made. Whilst the DBT skills group has been provided as a standalone treatment with this population and has

shown positive outcomes (e.g. Crossland et al. 2017; Sakdalan et al., 2010), it seems that participants benefitted from accessing the different modalities within DBT. Where possible, services should therefore aim to provide DBT in its entirety.

In order to support individuals to generalise newly acquired skills/knowledge, it may be beneficial to involve support staff/families within the DBT process. This is in line with the findings of Rose et al. (2005) who noted the benefits of involving support staff in therapy.

One participant spoke about valuing the reflections of an ex service-user who had previously undertaken DBT, and many individuals valued teaching others about DBT. Following completing DBT, services could therefore encourage individuals with lived experience of DBT to utilise their expertise, in line with service user involvement programmes.

With regards to future research, due to the growing qualitative research in this area, it may be beneficial to conduct a meta-ethnography in order to synthesise the available qualitative literature. Moreover, as some similarities across clinical settings (i.e. inpatient, forensic) were noted, synthesising the data may provide further insight around this.

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CHAPTER 3

PUBLIC DISSEMINATION DOCUMENT

THE OUTCOMES AND EXPERIENCES OF DIALECTICAL BEHAVIOUR THERAPY FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

This paper provides an overview of the systematic review and empirical research study carried out as part of the Doctorate in Clinical Psychology at the University of Birmingham.

Key terms

Intellectual disability (ID)- The term 'intellectual disability' refers to individuals with an intelligence quotient (IQ) of below 70. These individuals may have difficulties understanding information and learning new skills, in addition to struggling to manage independently. These difficulties will have been present since childhood (World Health Organisation, 2018).

Borderline Personality Disorder (BPD)- individuals with BPD typically experience intense emotions which can feel difficult to tolerate. They may lack the skills needed to manage these emotions effectively and therefore engage in impulsive behaviours such as self-harm and suicide attempts as a way of managing distress. Individuals also tend to experience difficulties within interpersonal relationships (Lieb et al., 2004).

Dialectical Behaviour Therapy (DBT)- DBT is a well-established and researched treatment for individuals with BPD. DBT acknowledges the difficult previous experiences that people with BPD are likely to have had, whilst also encouraging them to develop a range of more helpful coping skills (May, Richardi & Barth, 2016). A full DBT programme includes different components, including individual therapy, group sessions and access to telephone support. The clinicians delivering DBT also

attend regular meetings to support them with implementing the therapy effectively (Linehan, 1993).

Quantitative research- this involves examining numerical data (e.g. responses on a questionnaire or survey) and analysing this data using statistical methods.

Qualitative research- this is more exploratory and aims to develop an in-depth understanding of a particular experience/event/topic. This may involve carrying out interviews or focus groups with individuals.

Systematic Review: The outcomes of Dialectical Behaviour Therapy for individuals with Intellectual Disabilities

Background

Research supports the use of DBT as a treatment for individuals with BPD, however DBT is increasingly being utilised with a range of other populations and difficulties (Chapman, 2006). The National Institute of Health and Clinical Excellence (2009) recommends that individuals with mild ID and BPD should be able to access the same services as the wider population who have BPD. There are currently a limited number of studies which examine DBT for individuals with ID, however, this research area does appear to be gathering momentum (Crossland, Hewitt & Walden, 2017). In order to gain a greater understanding into the impact of DBT for individuals with ID, a review of the available research studies was carried out. The review aimed to examine the outcomes of DBT for people with ID.

Method

Electronic databases were systematically searched in order to identity relevant papers; 13 papers were identified and subsequently included in the review. The quality of each of the studies was evaluated using standardised checklists.

Results

The studies indicated that there were some positive outcomes following DBT for individuals with ID. This included a reduction in behaviours such as self-harming and aggression to others; participants also experienced improvements in their overall

wellbeing, mood and functioning. Other key findings were that participants were able to utilise the skills learnt in DBT in order to help them to more effectively manage difficult situations and emotions. A smaller number of studies reported findings such as increased self-esteem and feelings of hope for the future.

The review highlighted that there were a number of differences across the studies, including the type of treatment participants received (e.g. some only received the group sessions, whilst others received individual therapy, group sessions and telephone support), the length of time they received treatment for (e.g. this ranged from 13 weeks to 6.9 years) and the way treatment outcomes were captured (e.g. incident reports, questionnaires, interviews).

All of the studies reviewed appeared to be poor quality; some of main limitations were that they used a small number of participants, they did not utilise a comparison group and the reporting of important information was often lacking within the studies (e.g. participants ages, level of ID, diagnoses).

Conclusions

Due to the poor quality of the studies included in the review, we were unable to confidently conclude that DBT was responsible for the outcomes reported. It is therefore important that future research involves larger numbers of participants and utilises a comparison group, so that any outcomes following DBT can be more confidently attributed to the treatment. Future research would also benefit from greater standardisation and consistency across studies (e.g. the treatment received,

method for capturing outcomes) in addition to ensuring that all relevant information is reported within the paper.

Empirical Paper: Experiences of Dialectical Behaviour Therapy in a community setting for individuals with Intellectual Disabilities

Background

Whilst quantitative research can capture important information about outcomes/change following psychological treatment, it does not capture valuable information about the client's *experience* of therapy and the important processes within this (MacMahon et al., 2015). Understanding client experiences of therapy can lead to more effective interventions and give individuals a voice (Timulak & Keogh, 2017; McElvaney & Timulak, 2013). Historically, the views and experiences of people with ID have been largely overlooked and these individuals were rarely included in qualitative research (Cookson & Dickson, 2010). However, there appears to be greater recognition that the views and experiences of people with ID are valuable, 'worth hearing' and 'worth understanding' (Nind, 2008; Hoole & Morgan, 2010).

McNair, Woodrow & Hare (2017) suggested that it would be beneficial to carry out qualitative research to explore individuals with ID experiences of DBT. Some previous qualitative research has explored experiences of a DBT programme within inpatient or forensic settings, however, to date, we were unable to identify any qualitative papers which explored experiences of community-based DBT. This paper therefore aimed to explore the experiences of DBT in a community setting for individuals with ID.

Method

Eleven individuals with ID were recruited from two NHS Trusts and were interviewed about their experience of DBT. A method known as Interpretative Phenomenological Analysis (IPA) was used to analyse the interviews; IPA is an in-depth analysis, which examines how individuals make sense of major life experiences (Smith, Flowers and Larkin, 2009). IPA involves developing themes from the interview data, which capture interesting and important features and patterns across participants' narratives. In order to check the credibility and validity of the themes which emerged from the analysis, the themes were reviewed by clinicians independent to the study; the author also utilised supervision and attended IPA peer group meetings.

Results

Four main themes and nine corresponding sub-themes emerged from the analysis (see Table 12).

Table 12. IPA themes

Main Theme	**Sub-theme**
1. Experience of power	a) Having a voice in therapy b) A shifting position of power
2. Differences in therapy contexts	a) Openness and filtering b) Seriousness and playfulness c) Being in a group as challenging d) Being part of a group as rewarding
3. The experience of a positive therapeutic relationship	
4. A new way of being	a) Integrating DBT into life b) Change c) A shifting sense of self: old me and new me

Theme 1 captured accounts about the experience of power in DBT; individuals described having a voice in therapy, where they were able to assert their needs, exert control and show agency around their learning. Individuals valued the skills/knowledge acquired through DBT and this appeared to be associated with a sense of empowerment. Moreover, participants seemed to experience a shift in their position of power as part of the process of learning; they appeared to move from the

arguably more subordinate position of a learner, towards mastery of skills/knowledge, and then some took on the role of a teacher.

Theme 2 highlighted how participants made sense of the different therapy contexts (i.e. individual therapy, group sessions). These components appeared to meet different needs and were associated with different challenges and benefits. For example, in individual therapy, participants valued being able to talk openly without any limitation, and the content of what was discussed tended to be more serious in nature. Comparatively, they appeared to filter what they said in group sessions, but experienced them as more playful overall. Being in a group context was associated with feelings of anxiety, however it also provided a sense of belonging, opportunities for social interactions and the development of friendships.

Theme 3 focused on participants experience of developing a positive relationship which the therapist. Individuals described the qualities and attitudes of the therapist, which contributed to a relationship characterised by trust, validation, attunement, availability, empowerment and a non-judgemental stance.

Theme 4 explored the impact DBT had on participants. DBT appeared to have become a part of individuals day-to-day lives, whereby they were routinely and automatically utilising the skills they had learnt. Individuals noticed changes in their thoughts, emotions and behaviours, alongside improvements in their interpersonal relationships and feelings of empowerment. DBT also seemed to have changed their sense of how they saw themselves as people.

Conclusions

This study provides insight into the experience of DBT for people with ID. DBT appeared to be an empowering experience for individuals and findings highlight the distinct contributions of the different DBT components, alongside the importance of a positive therapeutic relationship and the subsequent impact therapy had on these individuals lives.

Participants dissemination document

For the participants who took part in the empirical research study, an accessible summary of the main findings was developed (Appendix 12).

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Glossary of terms

ADHD- Attention Deficit Hyperactivity Disorder

ASD- Autism Spectrum Disorder

BPD- Borderline Personality Disorder

BSI- Brief Symptoms Inventory

CAMS-R- Cognitive and Affective Mindfulness Scale–Revised

CBT- Cognitive Behaviour Therapy

CIRCLE- Chart of Interpersonal Reactions in Closed Living Environments

CRI- Coping Response Inventory

DBT- Dialectical Behaviour Therapy

DBTCFQ- The Dialectical Behaviour Therapy Carers' Feedback Questionnaire

DBT-SS- Dialectical Behaviour Therapy Skills System

ECQ- Emotional Control Questionnaire

EPS-BRS- Emotional Problems Scale-Behaviour Report Scale

GAD- Generalised Anxiety Disorder

GAS- Glasgow Anxiety Scale

GDS- Glasgow Depression Scale

HoNOS-LD- The Health of the Nation Outcome Scale– Learning Disability version

ID- Intellectual Disabilities

ID/D- Intellectual and developmental disabilities

IED- Intermittent Explosive Disorder

IPA- Interpretative Phenomenological Analysis

NHS- National Health Service

NICE- National Institute of Health and Clinical Excellence

OCD-Obsessive Compulsive Disorder

PD- Personality Disorder

PCP-Personal Construct Psychology

PTOS-ID- Psychological Therapies Outcome Scales—Intellectual Disabilities version

RBS- Risk Behaviour Survey

RCT- Randomised Controlled Trial

SCL-90-R- The Symptom Checklist-90-Revised

START- Short-term Assessment of Risk and Treatability

VABS-II- The Vineland Adaptive Behaviour Scales–Second Edition

Appendix 1. QualSyst Quantitative Checklist (Kmet et al., 2004)

Criteria		YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?				
2	Study design evident and appropriate?				
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				
14	Conclusions supported by the results?				

Definitions and Instructions for Quality Assessment Scoring

How to calculate the summary score

- **Total sum** = (number of "yes" * 2) + (number of "partials" * 1)
- **Total possible sum** = 28 – (number of "N/A" * 2)
- **Summary score:** total sum / total possible sum

Quality assessment

1. *Question or objective sufficiently described?*

   Yes: Is easily identified in the introductory section (or first paragraph of methods section). Specifies (where applicable, depending on study design) *all* of the following: purpose, subjects/target population, and the *specific* intervention(s) /association(s)/descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is *not* considered sufficiently described.

   Partial: Vaguely/incompletely reported (e.g. "describe the effect of" or "examine the role of" or "assess opinion on many issues" or "explore the general attitudes"...); *or* some information has to be gathered from parts of the paper other than the introduction/background/objective section.

   No: Question or objective is not reported, or is incomprehensible.

   N/A: Should not be checked for this question.

2. *Design evident and appropriate to answer study question?*

   (If the study question is not given, infer from the conclusions).

   Yes: Design is easily identified and is appropriate to address the study question / objective.

   Partial: Design and /or study question not clearly identified, but gross inappropriateness is not evident; *or* design is easily identified but only partially addresses the study question.

   No: Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); *or* design cannot be identified.

   N/A: Should not be checked for this question.

3. *Method of subject selection (and comparison group selection, if applicable) or source of information/input variables (e.g., for decision analysis) is described and appropriate.*

Yes: Described and appropriate. Selection strategy *designed* (i.e., consider sampling frame and strategy) to obtain an unbiased sample of the relevant target population or the entire target population of interest (e.g., consecutive patients for clinical trials, population-based random sample for case-control studies or surveys). Where applicable, inclusion/exclusion criteria are described and defined (e.g., "cancer" -- ICD code or equivalent should be provided). *Studies of volunteers:* methods and setting of recruitment reported. *Surveys:* sampling frame/ strategy clearly described and appropriate.

Partial: Selection methods (and inclusion/exclusion criteria, where applicable) are not completely described, but no obvious inappropriateness. Or selection strategy is not ideal (i.e., likely introduced bias) but did not likely seriously distort the results (e.g., telephone survey sampled from listed phone numbers only; hospital based case-control study identified all cases admitted during the study period, but recruited controls admitted during the day/evening only). Any study describing participants only as "volunteers" or "healthy volunteers". *Surveys:* target population mentioned but sampling strategy unclear.

No: No information provided. *Or* obviously inappropriate selection procedures (e.g., inappropriate comparison group if intervention in women is compared to intervention in men). *Or* presence of selection bias which likely seriously distorted the results (e.g., obvious selection on "exposure" in a case-control study).

N/A: Descriptive case series/reports.

4. *Subject (and comparison group, if applicable) characteristics or input variables/information (e.g., for decision analyses) sufficiently described?*

Yes: Sufficient relevant baseline/demographic information clearly characterizing the participants is provided (or reference to previously published baseline data is provided). Where applicable, reproducible criteria used to describe/categorize the participants are clearly defined (e.g., ever-smokers, depression scores, systolic blood pressure > 140). If "healthy volunteers" are used, age and sex must be reported (at minimum). *Decision analyses:* baseline estimates for input variables are clearly specified.

Partial: Poorly defined criteria (e.g. "hypertension", "healthy volunteers", "smoking"). *Or* incomplete relevant baseline / demographic information (e.g., information on likely confounders not reported). *Decision analyses:* incomplete reporting of baseline estimates for input variables.

No: No baseline / demographic information provided.
Decision analyses: baseline estimates of input variables not given.

N/A: Should not be checked for this question.

5. *If random allocation to treatment group was possible, is it described?*

Yes: True randomization done - requires a description of the method used (e.g., use of random numbers).

Partial: Randomization mentioned, but method is not (i.e. it may have been possible that randomization was not true).

No: Random allocation not mentioned although it would have been feasible and appropriate (and was possibly done).

N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.

6. *If interventional and blinding of investigators to intervention was possible, is it reported?*

Yes: Blinding reported.

Partial: Blinding reported but it is not clear who was blinded.

No: Blinding would have been possible (and was possibly done) but is not reported.

N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.

7. *If interventional and blinding of subjects to intervention was possible, is it reported?*

Yes: Blinding reported.

Partial: Blinding reported but it is not clear who was blinded.

No: Blinding would have been possible (and was possibly done) but is not reported.

N/A: Observational studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports.

8. *Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?*

Yes: Defined (or reference to complete definitions is provided) and measured according to reproducible, "objective" criteria (e.g., death, test completion – yes/no, clinical scores). Little or minimal potential for measurement / misclassification errors. *Surveys:* clear description (or reference to clear description) of questionnaire/interview content and response options. *Decision analyses:* sources of uncertainty are defined for all input variables.

Partial: Definition of measures leaves room for subjectivity, *or* not sure (i.e., not reported in detail, but probably acceptable). *Or* precise definition(s) are missing, but no evidence or problems in the paper that would lead one to assume major problems. *Or* instrument/mode of assessment(s) not reported. Or misclassification errors may have occurred, but they did not likely seriously distort the results (e.g., slight difficulty with recall of long-ago events; exposure is measured only at baseline in a long cohort study). *Surveys:* description of

questionnaire/interview content incomplete; response options unclear. *Decision analyses:* sources of uncertainty are defined only for some input variables.

No: Measures not defined, or are inconsistent throughout the paper. *Or* measures employ only ill-defined, subjective assessments, e.g. "anxiety" or "pain." *Or* obvious misclassification errors/measurement bias likely seriously distorted the results (e.g., a prospective cohort relies on self-reported outcomes among the "unexposed" but requires clinical assessment of the "exposed"). *Surveys:* no description of questionnaire/interview content or response options. *Decision analyses:* sources of uncertainty are not defined for input variables.

N/A: Descriptive case series / reports.

9. *Sample size appropriate?*

Yes: Seems reasonable with respect to the outcome under study and the study design. When statistically significant results are achieved for major outcomes, appropriate sample size can usually be assumed, unless large standard errors (SE > ½ effect size) and/or problems with multiple testing are evident. *Decision analyses:* size of modeled cohort / number of iterations specified and justified.

Partial: Insufficient data to assess sample size (e.g., sample seems "small" and there is no mention of power/sample size/effect size of interest and/or variance estimates aren't provided). *Or* some statistically significant results with standard errors > ½ effect size (i.e., imprecise results). *Or* some statistically significant results in the absence of variance estimates. *Decision analyses:* incomplete description or justification of size of modeled cohort / number of iterations.

No: Obviously inadequate (e.g., statistically non-significant results and standard errors > ½ effect size; or standard deviations > _ of effect size; or statistically non-significant results with no variance estimates and obviously inadequate sample size). *Decision analyses:* size of modeled cohort / number of iterations not specified.

N/A: Most surveys (except surveys comparing responses between groups or change over time). Descriptive case series / reports.

10. *Analysis described and appropriate?*

Yes: Analytic methods are described (e.g. "chi square"/ "t-tests"/"Kaplan-Meier with log rank tests", etc.) and appropriate.

Partial: Analytic methods are not reported and have to be guessed at, but are probably appropriate. *Or* minor flaws or some tests appropriate, some not (e.g., parametric tests used, but unsure whether appropriate; control group exists but is not used for statistical analysis). *Or* multiple testing problems not addressed.

No: Analysis methods not described and cannot be determined. *Or* obviously inappropriate analysis methods (e.g., chi-square tests for continuous data, SE given where normality is highly unlikely, etc.). *Or* a study with a descriptive goal / objective is over-analyzed.

N/A: Descriptive case series / reports.

11. *Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/objective upon which the conclusions are based)?*

Yes: Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). *Decision analyses:* sensitivity analysis includes all variables in the model.

Partial: Undefined "+/-" expressions. *Or* no specific data given, but insufficient power acknowledged as a problem. *Or* variance estimates not provided for all main results/outcomes. *Or* inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at "time 1" or "time 2", but does not provide an estimate of the variance around the difference). *Decision analyses:* sensitivity analysis is limited, including only some variables in the model.

No: No information regarding uncertainty of the estimates. *Decision analyses:* No sensitivity analysis.

N/A: Descriptive case series / reports. Descriptive surveys collecting information using open-ended questions.

12. *Controlled for confounding?*

Yes: Randomized study, with comparability of baseline characteristics reported (or non-comparability controlled for in the analysis). *Or* appropriate control at the design or analysis stage (e.g., matching, subgroup analysis, multivariate models, etc). *Decision analyses:* dependencies between variables fully accounted for (e.g., joint variables are considered).

Partial: Incomplete control of confounding. *Or* control of confounding reportedly done but not completely described. *Or* randomized study without report of comparability of baseline characteristics. *Or* confounding not considered, but not likely to have seriously distorted the results. *Decision analyses:* incomplete consideration of dependencies between variables.

No: Confounding not considered, and may have seriously distorted the results. *Decision analyses:* dependencies between variables not considered.

N/A: Cross-sectional surveys of a single group (i.e., surveys examining change over time or surveys comparing different groups should address the potential for confounding). Descriptive studies. Studies explicitly stating the analysis is strictly descriptive/exploratory in nature.

13. *Results reported in sufficient detail?*

Yes: Results include major outcomes and all mentioned secondary outcomes.

Partial: Quantitative results reported only for some outcomes. *Or* difficult to assess as study question/objective not fully described (and is not made clear in the methods section), but results seem appropriate.

No: Quantitative results are reported for a subsample only, or "n" changes continually across the denominator (e.g., reported proportions do not account for the entire study sample, but are reported only for those with complete data -- i.e., the category of "unknown" is not used where needed). *Or* results for some major or mentioned secondary outcomes are only qualitatively reported when quantitative reporting would have been possible (e.g., results include vague comments such as "more likely" without quantitative report of actual numbers).

N/A: Should not be checked for this question.

14. *Do the results support the conclusions?*

Yes: All the conclusions are supported by the data (even if analysis was inappropriate). Conclusions are based on all results relevant to the study question, negative as well as positive ones (e.g., they aren't based on the sole significant finding while ignoring the negative results). Part of the conclusions may expand beyond the results, if made *in addition to* rather than instead of those strictly supported by data, and if including indicators of their interpretative nature (e.g., "suggesting," "possibly").

Partial: Some of the major conclusions are supported by the data, some are not. *Or* speculative interpretations are not indicated as such. *Or* low (or unreported) response rates call into question the validity of generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).

No: None or a very small minority of the major conclusions are supported by the data. *Or* negative findings clearly due to low power are reported as definitive evidence against the alternate hypothesis. *Or* conclusions are missing. *Or* extremely low response rates invalidate generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).

N/A: Should not be checked for this question.

Appendix 2. QualSyst Qualitative checklist (Kmet et al., 2004)

Criteria		YES (2)	PARTIAL (1)	NO (0)
1	Question / objective sufficiently described?			
2	Study design evident and appropriate?			
3	Context for the study clear?			
4	Connection to a theoretical framework / wider body of knowledge?			
5	Sampling strategy described, relevant and justified?			
6	Data collection methods clearly described and systematic?			
7	Data analysis clearly described and systematic?			
8	Use of verification procedure(s) to establish credibility?			
9	Conclusions supported by the results?			
10	Reflexivity of the account?			

Definitions and Instructions for Quality Assessment Scoring

How to calculate the summary score

- **Total sum** = (number of "yes" * 2) + (number of "partials" * 1)
- **Total possible sum** = 20
- **Summary score:** total sum / total possible sum

Quality assessment

1. *Question / objective clearly described?*

   Yes: Research question or objective is clear by the end of the research process (if not at the outset).

   Partial: Research question or objective is vaguely/incompletely reported.

   No: Question or objective is not reported, or is incomprehensible.

2. *Design evident and appropriate to answer study question?*

   (If the study question is not clearly identified, infer appropriateness from results/conclusions.)

   Yes: Design is easily identified and is appropriate to address the study question.

   Partial: Design is not clearly identified, but gross inappropriateness is not evident; or design is easily identified but a different method would have been more appropriate.

   No: Design used is not appropriate to the study question (e.g. a causal hypothesis is tested using qualitative methods); or design cannot be identified.

3. *Context for the study is clear?*

   Yes: The context/setting is adequately described, permitting the reader to relate the findings to other settings.

   Partial: The context/setting is partially described.

   No: The context/setting is not described.

4. *Connection to a theoretical framework / wider body of knowledge?*

   Yes: The theoretical framework/wider body of knowledge informing the study and the methods used is sufficiently described and justified.

   Partial: The theoretical framework/wider body of knowledge is not well described or justified; link to the study methods is not clear.

   No: Theoretical framework/wider body of knowledge is not discussed.

5. *Sampling strategy described, relevant and justified?*

   Yes: The sampling strategy is clearly described and justified. The sample includes the full range of relevant, possible cases/settings (i.e., more than simple convenience sampling), permitting conceptual (rather than statistical) generalizations.

   Partial: The sampling strategy is not completely described, or is not fully justified. Or the sample does not include the full range of relevant, possible cases/settings (i.e., includes a convenience sample only).

   No: Sampling strategy is not described.

6. *Data collection methods clearly described and systematic?*

   Yes: The data collection procedures are systematic, and clearly described, permitting an "audit trail" such that the procedures could be replicated.

   Partial: Data collection procedures are not clearly described; difficult to determine if systematic or replicable.

   No: Data collection procedures are not described.

7. *Data analysis clearly described, complete and systematic?*

   Yes: Systematic analytic methods are clearly described, permitting an "audit trail" such that the procedures could be replicated. The iteration between the data and the explanations for the data (i.e., the theory) is clear – it is apparent how early, simple classifications evolved into more sophisticated coding structures which then evolved into clearly defined concepts/explanations for the data). Sufficient data is provided to allow the reader to judge whether the interpretation offered is adequately supported by the data.

   Partial: Analytic methods are not fully described. *Or* the iterative link between data and theory is not clear.

   No: The analytic methods are not described. *Or* it is not apparent that a link to theory informs the analysis.

8. *Use of verification procedure(s) to establish credibility of the study?*

Yes: One or more verification procedures were used to help establish credibility/trustworthiness of the study (e.g., prolonged engagement in the field, triangulation, peer review or debriefing, negative case analysis, member checks, external audits/inter-rater reliability, "batch" analysis).

No: Verification procedure(s) not evident.

9. *Conclusions supported by the results?*

Yes: Sufficient original evidence supports the conclusions. A link to theory informs any claims of generalizability.

Partial: The conclusions are only partly supported by the data. *Or* claims of generalizability are not supported.

No: The conclusions are not supported by the data. *Or* conclusions are absent.

10. *Reflexivity of the account?*

Yes: The researcher explicitly assessed the likely impact of their own personal characteristics (such as age, sex and professional status) and the methods used on the data obtained.

Partial: Possible sources of influence on the data obtained were mentioned, but the likely impact of the influence or influences was not discussed.

No: There is no evidence of reflexivity in the study report.

Appendix 3. Comprehension Questions

Comprehension Questions

1. What will Amy be interviewing you about?

Answer: The DBT programme*

2. Do you have to take part in this study?

Answer: No

3. If you agreed to take part, can you change your mind later on?

Answer: Yes

4. Will your name be used when Amy writes up her research?

Answer: No

If these questions are answered correctly, ask:

5. Is it OK for Amy to interview you?

Answer: If yes, provide the individual with the consent form to sign.

If no, do not give the consent form to the individual to sign.

* Change name depending on what each service called the DBT programme

Appendix 4. NHS Research Ethical Committee Approval letter

NHS
Health Research Authority

Miss Amy Pearson
School of Clinical Psychology, Department of Psychology
University of Birmingham, Edgbaston
Birmingham
B15 2TT

Email:

12 October 2017

Dear Miss Pearson

Letter of HRA Approval

Study title:	**Dialectical Behavioural Therapy (DBT) for individuals with Learning Disabilities in a community setting: service user and staff experiences**
IRAS project ID:	**219261**
REC reference:	**17/WM/0288**
Sponsor	**University of Birmingham**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to [redacted]
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

IRAS project ID	219261

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-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **219261**. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed (Sent on behalf of Isobel Lyle)
Assessor

Telephone:
Email:

Copy to: *Dr Sean Jenning, Sponsor contact, University of Birmingham,*

Appendix 5. NHS Trust X Research and Development ethical approval

[redacted] NHS
NHS Foundation Trust

[redacted]

Amy Pearson
Post Trainee Clinical Psychologist
School of Psychology
University of Birmingham
Edgbaston, Birmingham
B15 2TT

Tel [redacted]

30 October 2017

Dear Amy

Name of project - Experiences of DBT for individuals with Learning Disabilities

Thank you for providing us with the documentation to support your application for [redacted] Research & Innovation approval. We have received notification of a favourable ethical opinion and following a review of all the documentation this study has been approval by this Trust. You may therefore commence the work.

Please note that the Trust's approval of this research is given on the understanding that you are aware of and will fulfil your responsibilities under the Department of Health's Research Governance Framework for Health and Social Care, including complying with any monitoring/auditing of research undertaken by the R&I Department.

In particular, whilst conducting your study you should respect the confidentiality of data obtained from participants.

Please do not hesitate in contacting the Research & Innovation Team, contact details above should you require any advice or support on any aspect of your project.

I would like to wish you every success with your research and look forward to receiving a copy of your completed report in the future.

Yours sincerely

[redacted]

Appendix 6. NHS Trust X Research and Development ethical approval

From: [redacted]
Sent: 07 November 2017 10:48
To: Amy Pearson
Subject: Re: R&D Approval / Capacity & Capability approval for Study IRAS 219261 - Dialectical Behavioural Therapy (DBT) for individuals with Learning Disabilities in a community setting: service user and staff experiences..

Dear Amy,

Re: IRAS 219261 - Confirmation of Capacity and Capability at [redacted]

Full Study Title: Dialectical Behavioural Therapy (DBT) for individuals with Learning Disabilities in a community setting: service user and staff experiences.

-

This email confirms that [redacted] has the capacity and capability to deliver the above referenced study.

This study has been reviewed at [redacted] and can be implemented.

We agree to start the study from 07 November 2017.

If you wish to discuss further, please do not hesitate to contact me.

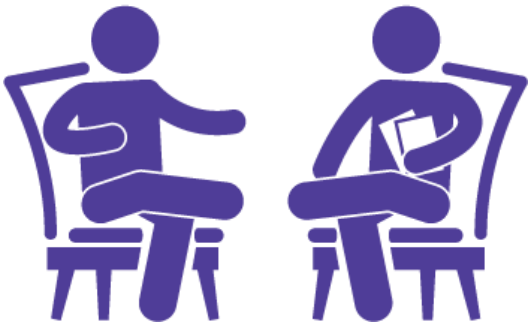
Kind regards,

[redacted]
Research Facilitator
[redacted]
Research and Development

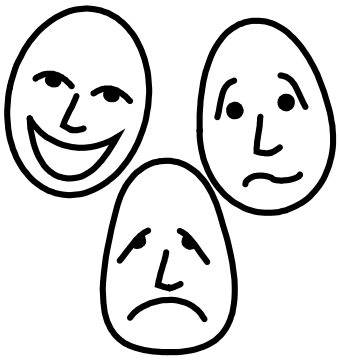
Tel: [redacted]
Fax

Appendix 7. Information Sheet

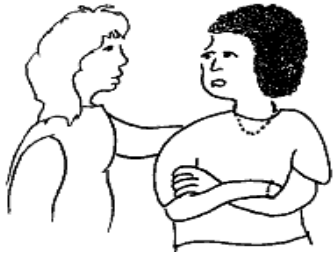
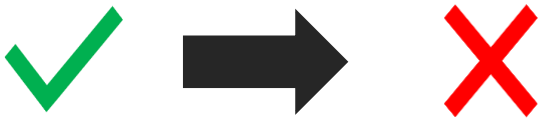
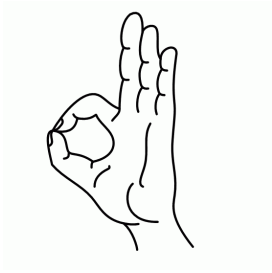
Information Sheet

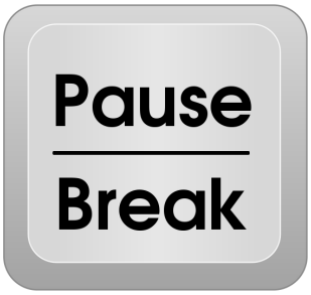
	This is Amy She is training to be a Clinical Psychologist at Birmingham University
	She is going to be doing some research
	Amy would like to interview people with Learning Disabilities, who have had Dialectical Behavioural Therapy (DBT)*

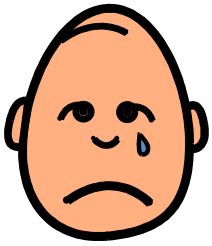
*Change name depending on what each service called the DBT programme

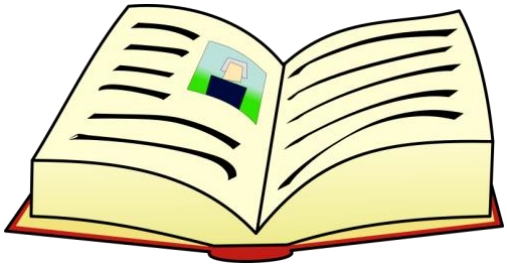
	Amy will ask you some questions about what was good in DBT*
	And what could have made it better
 **change picture depending on what images were used in each service	She will talk to you about what skills and ideas you learnt
	And what changes you noticed in yourself

	By asking these questions, Amy can understand how DBT* could be improved in future
	If you would like to talk to Amy about DBT*
	We will arrange a time for Amy to meet with you
	Amy will ask your permission to interview you and you will then sign a form

	Amy and other staff members will not mind if you say no
 	And if you do agree to take part in an interview, then later change your mind
 	This is ok too
	If you choose to take part, Amy will record the interview
	Then listen to the recording afterwards

	She will write down the conversation, then destroy the tape
	Your name will be kept private and no names will be used in the research
	If you become upset during the interview
	You can have a break and leave the room if you want to

	You can also stop the interview completely
	After the interview, Amy will check how you are feeling
	If you tell Amy that you might harm yourself or someone else
	Or if you have told Amy that something dangerous or illegal has happened in the past And staff do not know about it already

	Then Amy will speak to other staff members and make sure that you have support
	Amy and other staff will also be around after the interview if you want to talk
	After all the interviews have been done, Amy will write up what she has found
	You can have an easy-read copy of Amy's research if you would like one



If you have any questions, you can contact Amy:



Telephone [redacted]



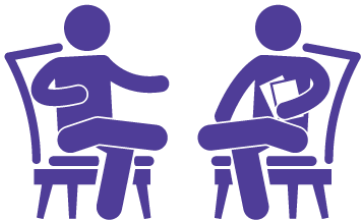
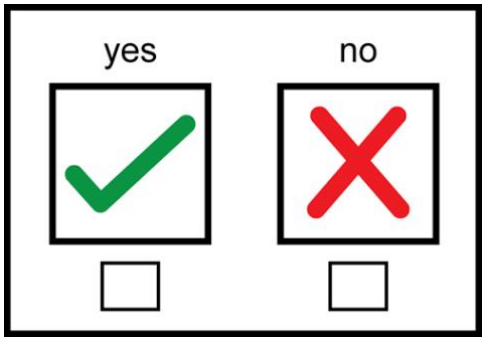
E-mail [redacted]



Post- School of Clinical Psychology, Department of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Appendix 8. Consent Form

Consent form

	I agree that Amy can interview me about DBT*
	I know that I do not have to take part
	I know that it is OK if I change my mind about talking to Amy
	I know that my name will be kept private

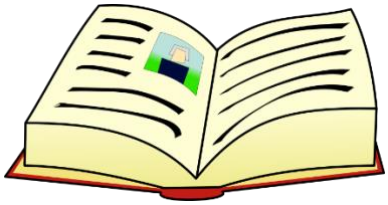
*Change name depending on what each service called the DBT programme

If you agree, please sign your name:

Signed……

Name……

Date……



Please tick here if you would like to receive an easy-read summary of the research once it has been written ☐

If you would like to receive a summary, please tick where you would like this to be sent to:



Email address ☐



Home address ☐



Service ☐

If you would like this sent to your email address or home address, please provide this information below:

☐

Appendix 9. Interview Schedule

Interview Schedule

I would like to talk to you about the DBT* treatment which you had in this service, as I am interested in finding out what you thought about it.

Can you tell me why you first came to the DBT programme? *(prompt and explore)*
Example prompts:

-What did you think the treatment could help you with? What did others say the treatment could help with?
-What kind of difficulties had you been having?
-Did you have any goals before you started?
-How did you feel before starting the programme? What did you think about coming?

Can you tell me about the DBT treatment? *(prompt and explore)*
Example prompts:

-What was the DBT programme was like?
-What did you like about it? What did you not like about it?

I want to ask you about the different parts of the DBT programme. Can you tell me about the skills group? *(prompt and explore)*
Example prompts*:*

-How did you find the group skills sessions?
-What did you do in the group? What did you learn? (ask for examples)
-Ask about the 4 different modules in the group
-Are there any parts which have stuck with you? (why?)
-Are there any parts which are harder to remember? (why?)
-How much of the session made sense/did you understand? (what helped/made it more difficult?)
-How did you feel each week before/during/after the sessions?
-What did you like most/least about the group skills sessions? (why?)
-What could have made the group skills sessions better?
-How did you feel about being in a group? What were the other people in the group like?
-What do you think other people would say about the group skills sessions?

Can you tell me about the individual therapy? *(prompt and explore)*
Example prompts:

-What was individual therapy like?
-What did you like most/least about it? (why?)
-What would have made it better?
-How did you find working with a therapist? What was your relationship with them like?
-Did they do or say anything that was helpful/unhelpful? How did this make you feel?
-How do you think other people found individual therapy?

-What was it like having individual therapy as well as group skills sessions?
-Were there any similarities/differences between group work and individual sessions?

What was it like during the week in the time between treatment sessions? *(prompt and explore)*

Example prompts:

-How were things at home in this time? How did you feel?
-Were you able to try new skills out/do homework in between sessions? (ask for examples)
-What made this easier/harder for you to do?
-Did you have any contact with therapists in between sessions over the phone? When/why would you call? How was this telephone contact?

Once you had finished the DBT treatment, what changes did you notice in yourself? *(prompt and explore)*

Example prompts:

-Did anything get any better/worse? (ask for examples)
-Did anyone else notice any changes in you? (ask for examples)
-How would we/you know that treatment had been useful for you? Ask what would be different in terms of thoughts/feelings/behaviour/physical/4 group skills modules
-What changes did others on the programme notice in themselves? Did you see changes in them? What was this like for you?
-How are things for you these days?

We have spoken about the different parts of the DBT programme and the changes you saw in yourself and others following treatment. I now want to ask you a few final questions about what you think of the DBT programme overall? *(prompt and explore)*

Example prompts:

-What did you like most/least about it?
-What would you tell a friend about it?
-Would you change anything about it?
-If you could change/keep one thing, what would you change/keep?
-Could anything be made more accessible for people with learning disabilities?
-If you were going to do the programme again, would you do anything differently?
-What would your advice be to someone thinking about doing the DBT programme?
-Is there anything else you would like to tell me about your experience?

Feedback following interview

How was that for you?
How are you feeling now?
Are there any other questions you think I should ask other service users in future interviews?

*use the term that the service uses for the DBT programme

Appendix 10. Example extract of coded data

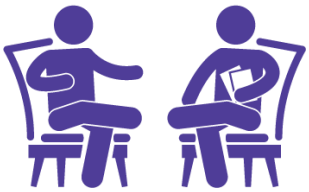
Emergent Themes	Transcript	Exploratory Comments
Improvement in interpersonal relationships	David: Where they would stay clear of me, they are coming over and talking to me Interviewer: What's that like for you?	Previously others would purposely avoid him/not go near him. Others are now approaching him and initiating conversation/ engaging in verbal interactions. He now appears more approachable to others? Others feelings and behaviors towards him have changed? Social relationships improved.
Strange relational experience	David: Strange Interviewer: In what way?	Feels strange that others would want to be around him? Unusual experience being approached by others?
Questioning others wanting to be friends Positive feedback from others Changed as a person	David: I haven't got money, I haven't got personal objects they would want... why are they trying to make friends? So I ask them, I goes "why are you so interested in me?" He goes "you're a different person. I don't know what you're doing, or where you are getting your personality from lately, but it's a good thing". Interviewer: How did you feel when you heard that?	Belief that others only want to be around you, if they can gain something? Beliefs that others only want money/goods from you? Others use you? Questioning why they would want to be friends. Mistrustful. Unsure of their motive. Novel experience. Directly ask people for their reasoning. Recognition/feedback from others that he has changed. Seen as a different person. Positive feedback. The change in him is seen as positive by others.
Impact of others on sense of self and mood	David: Again, it was another ego boost. You know my heels come off the floor like (laughs)	Sense of self was boosted. Second time referring to an ego boost in context of others. First was in relation to helping others, second in relation to receiving praise from others. Others words/actions have the ability to make you feel like

	Interviewer: (laughs) Ok	you can fly/floating on air? Positive relationships and feedback from others are important?
	David: Have we got enough time? Interviewer: Yeah we are running a little bit short of time, but I just wanted to ask you about the 1-1's. How did you find the 1-1's?	Showing awareness of time. Potential time constraints on the interview. Importance of staying on track. Referred to this following making a joke.
Positive 1-1 experience Honesty and openness Directness in 1-1	David: The 1-1's are brilliant, I can be as honest and as open and I am as open and as honest. You know I don't keep nothing back, I shoot from the hip. You know if its black, I say its black, you know I don't keep nothing back Interviewer: So how does it differ from the group skills?	Individual therapy brilliant. Able to be extremely honest and open. The value of openness and honesty. Does not hold back. Holds back in other settings? Speech is direct, blunt, frank, no careful consideration of words in 1-1. Unfiltered in 1-1?
Adapt self in the group Impact of self on others Offloading in 1-1 Therapist non-judgmental	David: You have to be conservative with the group, because with a group, they can take offence. With [the therapist], she can sit you down and say there's only two of us in here, get it off your chest. And by heck do I get it off my chest. And that's the thing with [the therapist], she doesn't judge what you say and that's where it works	There is a need to act conservatively in the group. Adapt self. Consideration and moderation of how you are/what you say. Others may take offence. Impact on others. Comparison of the 1-1 and group context. The number of people present is important? Therapist gives permission to offload. Indulges in the therapists offer. Offloading, open. What you say is not judged by the therapist. Therapy/the relationship with the therapist 'works' due to the non-judgmental stance. Group is judgmental? Group judge what you say?

Appendix 11. Prevalence of superordinate themes

Superordinate Theme	Number of participants contributing to the theme	Participants contributing to the theme
Experience of power	10	Evelyn Tess Katherine Harry David Helen Roger Emily Barbara Carole
Differences in therapy contexts	11	Evelyn Tess Katherine Harry David Sandra Helen Roger Emily Barbara Carole
The experience of a positive therapeutic relationship	9	Evelyn Tess Katherine Harry David Sandra Roger Emily Barbara
A new way of being	11	Evelyn Tess Katherine Harry David Sandra Helen Roger Emily Barbara Carole

Appendix 12. Participant dissemination document

	Amy works at Birmingham University
	She was doing some research about Dialectical Behaviour Therapy (DBT)* for people with Learning Disabilities
	Amy interviewed people with Learning Disabilities who have had DBT*
	She has now finished her research and written up what she found

*Change name depending on what each service called the DBT programme

What did Amy find out?





Before coming to DBT* people were finding it hard to:

- manage difficult feelings
- manage difficult situations
- have good relationships with other people



People wanted to learn new ideas and skills to manage better



They said DBT taught them lots of new ideas and skills



Some of these things were difficult to understand at first

	But people were able to say when they did not understand
	And ask for help
	As time went on things got easier
	Having all these new ideas and skills made people feel happy

What else did Amy find out?

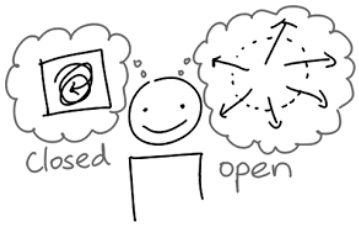




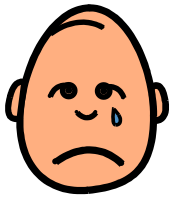
People spoke about the different parts of DBT*

Like the one-to-one sessions

And the group sessions

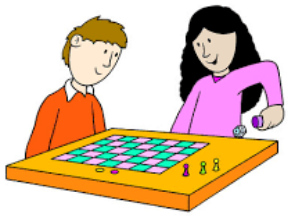






When talking about the **one-to-ones**, people said:

- they could be open and honest
- they could talk about anything
- sessions were sometimes upsetting

	When talking about the **group sessions**, people said: • they were more careful about what they said in the group
	• they felt nervous being in a group with other people
	• they had fun and enjoyed the games and activities
	• they made friends and liked being with people similar to them

What else did Amy find out?



People spoke about their **relationship with the DBT* staff**

They said that the staff:



- listened



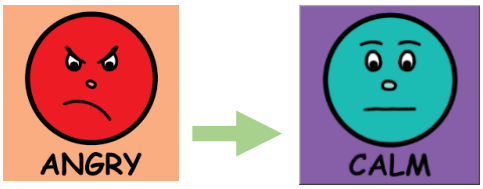
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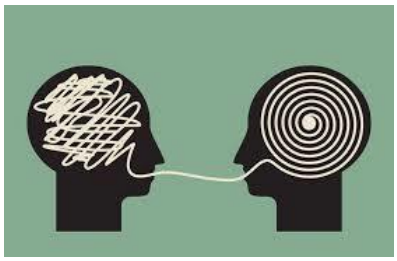
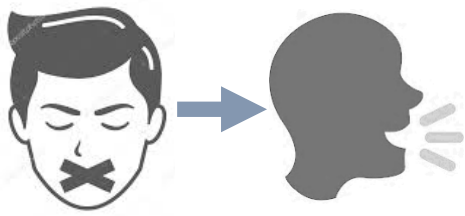


- were trustworthy

	• treated them like equals
	• did not judge them
	• were there when they needed them

What else did Amy find out?

	People said they had noticed lots of **changes** after doing DBT
	The new skills they learnt had become part of their everyday lives
	People said they were feeling calmer and not as angry

	People said there were changes in how they were thinking
	People said they were not hurting themselves anymore
	People were arguing less and getting on better with others
	People said they did not have to put up with things they were unhappy about anymore and could speak up

Message from Amy

	Amy is very happy that you spoke to her about DBT*
	She would like to say thank you for taking part in her research
	Amy will not need to come back and talk to you again

What will happen next?

	You can keep this booklet and read it again if you want to
	If you want to ask Amy any questions, you can ask a member of staff to call her
	Or you can speak to **(insert name of research collaborator at each site)