

**Developing an Understanding of the Impact of Dialectical Behaviour Therapy
on Adults with an Intellectual Disability with Emotion Regulation Difficulties**

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Declaration

I declare that the present research reported is my own work and has not been submitted for any other academic award.

Thesis Abstract

Literature Review

A systematic review of the literature on the use of Dialectical Behaviour Therapy (DBT) with adults with intellectual disabilities (ID's) was conducted. The question of effectiveness was examined but a lack of hard evidence indicated that the results were inconclusive. Whilst acknowledging this all the authors offered a consistent view that DBT was an effective intervention for this population.

Research Report

This research explored clients', carers' and therapists' experiences of DBT in a community learning disability service. This service is offered to individuals with 'Mild' to 'Moderate' intellectual disabilities with severe emotion regulation difficulties and who are a risk to themselves or others as a consequence of their behaviours. Three separate focus groups were undertaken with groups of clients, carers and therapists. The group transcripts were analysed using Interpretative Phenomenological Analysis. Similarities in experience across the three groups were identified resulting in three super-ordinate themes of 'change', 'it's painful' and 'development'. These themes suggest that all those who participate in an intellectual disability DBT service will experience change and develop personally and that this process is difficult. The clinical implications of this research support the use of DBT for adults with intellectual disability however it highlights the need for further adaptations to the DBT service in order to improve its effectiveness. Areas for future research are also discussed.

Critical Appraisal

This paper provides a detailed critique of the methodology and limitations of the research. It provides the researcher's reflections on the entire research process, elaborating on the decision-making processes involved and the personal impact of conducting the research.

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Word Count

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Section Three: Critical Appraisal	4,218	349	4,567
Section Four: Service Evaluation	4,754	491	5,245
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Section One: Literature Review

Dialectical Behaviour Therapy and Adults with an Intellectual Disability; an Evaluation

Abstract

Introduction

NICE guidance recommends dialectical behaviour therapy (DBT) for women with borderline personality disorder (BPD). The guidance also states that “When a person with a mild learning disability has a diagnosis of BPD, they should have access to the same services as other people with borderline personality disorder” (NICE, 2009, p.344). The recommendation that people with mild intellectual disabilities have access to DBT and the implicit assumption that it will be equally effective is based on a limited body of work. The aim of this review is to examine the current literature regarding the use of DBT with individuals with intellectual disabilities.

Method

A systematic review of the literature on the use of Dialectical Behaviour Therapy with individuals with an intellectual disability was carried out using electronic databases; PsycINFO, PsycEXTRA, PsycArticles, Web of Science, Medline, The BPS, Scopus and Social Care Online.

Results

The papers presented in the current review are suggestive that individuals with an intellectual disability benefit from the treatment of DBT. A number of methodological concerns have been identified and therefore caution must be exercised when interpreting the effectiveness of DBT with this client group.

Conclusion

DBT is relatively a new therapy for an intellectual disability population and because of the lack of research the evidence to date is inconclusive. It should be noted however that a consistent view provided by all the authors reviewed, even after acknowledging study weaknesses, was that DBT was an effective intervention for this population.

Key Words: Learning Disability; Intellectual Disability and Dialectical Behaviour Therapy

1 Introduction

DBT is a psychotherapy originally developed by Marsha Linehan as an outpatient treatment for women with a diagnosis of borderline personality disorder (BPD) in the US. Linehan has described it essentially as a technology of change integrated with a technology of acceptance by means of dialectical principles, (Linehan, 1993). Behaviourist theory and techniques provide the technology of change and Zen Buddhist principles and practice the technology of acceptance. These seemingly contradictory approaches are integrated using the philosophical approach of dialectics, in particular the principles of inter-relatedness and wholeness, polarity and continuous change (Baillie & Slater, 2014).

In DBT the therapist has five main tasks: to increase the client's emotion regulation skills; to encourage the client to change behaviour; to support the generalisation of new behavioural skills; to develop treatment environments that support progress and through peer supervision facilitate capable and motivated therapists (Linehan, 2000). These tasks are addressed through four main modes of treatment: individual therapy, skills training group, telephone consultation, supervision and/or case consultation groups. DBT does not limit itself to these modes of treatment, in fact, Linehan argues in her seminal text that "in principle, DBT can be applied in any treatment mode" (1993, p. 101). An understanding that these modes may be condensed or supplemented is also acknowledged, for example, clients will also likely receive an ancillary treatment such as pharmacology. (Linehan, 1993).

BPD is referred to as an 'emotionally unstable personality disorder, borderline type' in the tenth revision of the International Classification of Diseases and related health problems manual (ICD-

10) and is characterized by “a marked tendency to act impulsively and without consideration of the consequences” (World Health Organization, 1993, p.204). Two types of presentation are identified; ‘the impulsive type’ and the ‘borderline type’. The individual experiencing the impulsive type is described as being dominated by emotional instability and a lack of impulse control. The individual experiencing the borderline presentation is described as having both of these characteristics and additionally experiences disturbance in self-image, chronic feelings of emptiness, intense and unstable interpersonal relationships, and a tendency to self-destructive behaviour (World Health Organization, 1993).

The DBT approach explains these affect regulation problems by using a transactional bio-social theory. That is, individuals with a BPD diagnosis are born with a biological emotional vulnerability and raised in an invalidating environment defined as “one in which communication of private experiences is met by erratic, inappropriate, and extreme responses”. (Linehan, 1993, p.49). In this environment, the expression of affects and cognitions are not validated, in fact, these expressions are often punished or ridiculed.

1.1 The psychological consequences of disordered development

A significant body of literature exists exploring the impact of the psychosocial conditions associated with intellectual disability and their impact on the development of early psychological processes and emotional development. Much of the research supports the presence of abnormal developmental processes in children with an intellectual disability (Royal College of Psychiatrists, 2004). Across the research different psychological processes are emphasised, however, there is a general consensus that there is slower development of self and object constancy, that emotional attachments can be subject to fragility and that the process of

separation–individuation from the caregiver is significantly affected (Levitas & Gilson, 1988; Gaedt, 2001; Whittaker, 2001). Examples include the typical experience of lifelong dependency upon others and the additional burdens placed upon individuals with fragile psychological defences by societal demands (Menolascino, 1990). Significant family dynamics such as ‘loss’ can also have a direct impact on development. Parents and other family members can have difficulties dealing with grief for the loss of the ‘perfect child’ that was hoped for but never arrived (Bicknell, 1983; Davis, 1987; Oswin, 1991). Individuals with intellectual disabilities are more likely to experience abuse (Cooke & Sinason, 1998), and as a consequence the significant psychological consequences of abuse. The psychosocial conditions described above are not an exhaustive list but representative of the factors described in the literature to provide understanding of the vulnerability of the intellectual disability population to significant rates of mental health problems (Royal College of Psychiatrists, 2004; Lew, 2011).

1.2 Historical perspective

Historically, the view has been that psychotherapy will not work for people with an intellectual disability. In fact a commonly held opinion was that people with an intellectual disability do not have the same need for psychotherapy as those in the general population (Charlton & Dykstra, 2011). In recent years it has become known that individuals with intellectual disabilities suffer from the same difficulties as the general population (Charlton, Kliethermes, Tallant, Taverne, & Tishelman, 2004; Butz, Bowling, & Bliss, 2000; Nezu & Nezu, 1994).

Since the late 1990’s DBT has been used with a variety of clinical populations and diagnoses, including depressed older adults, inpatients forensic populations, suicidal adolescents, binge eating disorders and substance misuse (Lynch, Morse, Mendelson, & Robins, 2003; McCann &

Ball, 1996; Telch, Agras, & Linehan, 2000; Linehan, Dimeff, & Reynolds, 2002). In 2009 the National Institute for Clinical Excellence (NICE) issued clinical practice guideline 78 which recommended Dialectical Behaviour Therapy (DBT) for women with BPD who are self-harming (Section 10.3.4.5). The guideline also stated that “When a person with a mild intellectual disability has a diagnosis of borderline personality disorder, they should have access to the same services as other people with borderline personality disorder” (Section 10.1.2.2) (NICE, 2009, p.378). This clearly provides a mandate for the use of DBT for individuals with an intellectual disability.

1.3 Definition of Disability

The term intellectual disability will be used throughout this review. This term refers to a person who meets the following criteria;

- A significantly impairment of intellectual functioning (an IQ score below 69)
- A reduced ability to cope independently (impaired social/adaptive functioning)
- Age onset before adulthood (18 years), with a lasting effect on development

(British Psychological Society, 2000)

1.4 Prevalence of Borderline Personality Disorder

Estimates of the prevalence of personality disorder in the general population ranges from 2% (World Health Organization, 1993; American Psychiatric Association (APA), 1994) to 9.1% with specific prevalence rates for borderline personality disorder estimated at 1.4%, (Lenzenweger, Lane, Loranger & Kessler 2007).

The prevalence figures regarding personality disorder for individuals with intellectual disability range from 1% (Deb & Hunter, 1991) to 91% in community settings (Naik, Gangadharan, & Alexander, 2002; Goldberg, Gitta, & Puddephatt, 1995; Khan, Cowan, & Roy, 1997) and between 22% (Reid & Ballinger, 1987) to 92% for inpatient settings (Flynn, Matthews, & Hollins, 2002). Moreland and her colleagues argue that this significant variation in the range of these findings is too large to be explained by real differences. They suggest that several factors including; “diagnostic overshadowing, delayed development of personality maturation, difficulty associated with diagnosis and inadequacies of measures and diagnostic tools” contribute to variation, (Moreland, Hendy, & Brown, 2008, p.224). Therefore these findings need to be viewed with caution.

1.5 Diagnosis of Personality Disorder in People with Intellectual Disabilities

A number of concerns have been raised in respect of making a diagnosis of personality disorder for adults with an intellectual disability and these have been considered in the following literature (Eaton & Menolascino, 1982; Alexander & Cooray, 2003). These include potential diagnostic overshadowing; a process in which the primary diagnosis of intellectual disability overshadows the recognition of other difficulties. For example, the features associated with BPD may be overshadowed by such presentations as self-injury, impulsivity and affective liability as these are common presentations associated with people with intellectual disabilities.

In addition the diagnostic criteria identified in both classification systems ICD-10 (WHO 1993) and DSM-IV (APA 1994) for many personality disorders have the potential to overlap with many of the typical characteristics of individuals who have a developmental disorder (Moreland et al, 2008). For example, it was claimed by Craft, that Schizoid Personality disorder (SPD) is

common amongst individuals with an intellectual disability (Craft, 1959). However, a review of this research carried out by Deb & Hunter argued that the vast majority of individuals identified as having SPD were in fact on the autistic spectrum (Deb & Hunter, 1991).

The typical methodological approaches used to diagnose personality disorder, for example, diagnostic interviews and or assessment tools have also received several criticisms. It has been argued that the interview approach is subject to several biases that occur because of interviewer variables such as “paraphrasing, selectively ignoring responses and difficulty in understanding client idiosyncrasies. Respondent variables would include impaired communication, differences between proxy and self-reports, acquiescence and recency effects” (Moreland et al, 2008, p.221). An example of the difficulties that interviewers can experience was described by Kroese, Dewhurst & Holmes (2001) who provided three examples of people who were thought to be experiencing hallucinations based on self-reports due to a lack of expressive ability. Additionally a paucity of reliable diagnostic tools and significant variation in their use has exacerbated these methodological difficulties (Kroese et al, 2001; Alexander & Cooray, 2003).

An examination of these issues within the neuro-typical population by Blackburn, noted that “the failure of different measures of the same disorder to agree, partly reflects imprecise definitions of the criteria, but a more critical issue is the validity of the current classification itself” (2000, p14). Therefore, when we consider the validity of the process of assessment and measurement of personality we need to examine it through the lens of its construct validity (Moreland et al, 2008). Four factors need to be considered;

1. The precision of the definitions of the diagnostic constructs.
2. The evidence base and empirical support for the components of the classification.
3. The ability of tools to distinguish themselves from other tools that are measuring different constructs whilst reliably measuring the same constructs.
4. The predictive ability of tools to measure behaviour and treatment outcomes.

Allowing for the criticisms described, there is still a general consensus that individuals with an intellectual disability are more vulnerable to personality disorder than the neuro-typical population (Alexander & Cooray, 2003; Dosen & Day, 2001). Torr (2003) argues that for individuals with both intellectual disability and personality disorder the impact of the personality disorder presentation is greater than the impact of intellectual disability and that these people need significant care and support.

1.6 Rationale of the Present Review

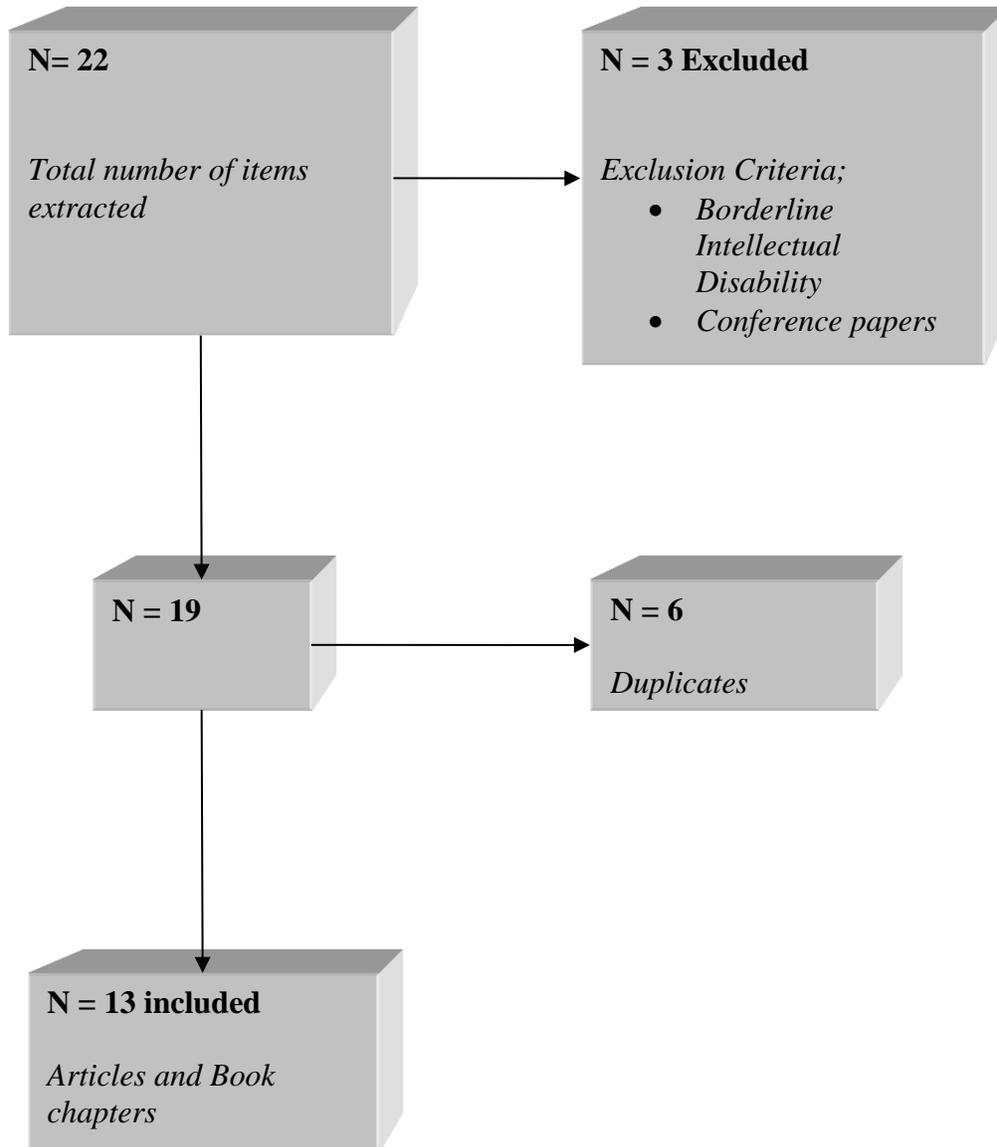
NICE clinical practice guideline 78 issued in 2009, clearly provides a mandate for the use of DBT for individuals with an intellectual disability. Even allowing for the range of prevalence rates it appears that there are numbers sufficient to highlight the potential need for specialist services such as DBT. The current review will examine all existing literature pertaining to the use of DBT with individuals with intellectual disabilities and will explore the evidence for its effectiveness with this client group.

2 Method

A comprehensive and systematic review of the literature concerned with the use of DBT with individuals with an intellectual disability was conducted between May 31st 2012 and February 4th 2016. The review included a search of the following electronic databases PsycINFO; PsycEXTRA; PsycArticles; Web of Science; Scopus; Medline; Social Care Online and the British Psychological Society's (Professional Society). In order to reduce the risk of missing any relevant studies due to the choice of search terms the articles' reference sections were searched on the selected databases.

A combination of the search terms 'Learning Disabilities', 'Intellectual Disability', 'Dialectical Behaviour Therapy', 'Mental Retardation' and their derivatives was used. These terms were selected with reference to the review question in order to achieve the broadest possible search. This review included any article and book chapter which referred to or discussed the use of DBT with an individual with an intellectual disability. Due to the paucity of literature in this field the only limiters applied to the search were to only include articles in the English language and only articles from 1993 onwards as this was the year the DBT model was introduced. Literature using Borderline Intellectual Disability client samples was also excluded. The search returned a total of 19 finds and of these six were excluded. Two on the basis that they were conference papers, one because the sample group was made up of adults with borderline intellectual disabilities and three because these were duplicates. Following this process thirteen items were identified as relevant. This included ten articles and three book chapters. (Figure 1).

Figure 1. Flow Chart of Systematic Review Process



2.1 Quality Appraisal

The appraisal was carried out using the ‘quality assessment tool for quantitative studies’ (National Collaborating Centre for Methods and Tools, 2008). This decision was based on the suitability of this tool for non-randomised studies and demonstrates acceptable validity and reliability properties (Thomas, Ciliska, Dobbins & Miccucci, 2004). This tool had also been selected as a suitable measure in a systematic review of quality assessment tools carried out by Deeks et al (2003). It provides a standardised means to assess the quality of studies with an outcome of an overall rating of either strong, moderate or weak. The overall rating is based on an assessment of six areas: study design, confounders, blinding, data collection methods, and withdrawals and drop-outs (see Table 5). The three book chapters were excluded from this process as these contained were lengthened descriptions of the research published in their papers.

3 Results

3.1 General Description

The thirteen items included in the present review consisted of ten articles and three book chapters. The databases, key words, number of finds and limiters are produced in Table 1. Summaries of the aims of the 10 articles, participants involved, measures used and conclusions drawn have been ordered by date of publication and have been numbered 1-10 with 1 being the oldest. (Table 2). A summary of the aims and conclusions of the three book chapters has been produced (Table 3). The articles are reviewed in terms of their samples, modes of treatment, evaluation methods used and the evaluation results found.

4 Sample

The number of participants receiving some form of DBT input across the articles totalled 127. Sample sizes ranged from 2 to 40. In respect of gender, where this information was provided, 76 of 100 participants that is 76% of their participants were male (Lew, Matta, Tripp-Tebo, & Watts, 2006), (Sakdalan, Shaw, & Collier, 2010), (Morrissey & Ingamells, 2011), (Sakdalan & Collier, 2012), (Brown, Brown & Dibiasio, 2013), (McNair, Woodrow & Hare, 2015) and (Baillie & Slater, 2014) (It is important to note here that the participants in Sakdalan and Collier's 2012 study had also participated in their 2010 pilot and as such are counted once in these figures). This high number of male participants is of particular note as this is almost the exact reverse of what was understood about gender differences at the time Marsha Linehan was developing DBT. Linehan referred to a review undertaken by Widiger & Frances (1989) which examined 38 studies and reported that 75% of the patients who met the criteria for BPD were women. These gender findings led Linehan to develop DBT as a therapeutic approach for women with BPD but with the hypothesis that this approach "may be effective for men" (Linehan, 1993, p.4) One must be mindful however, that the reported gender statistics were based on assessments and diagnosis in the clinical settings where women were more likely to present for treatment (Bjorklund, 2006). The figures presented in this paper, indicating a higher ratio of males to females, are likely also to be influenced by the clinical setting as it is not unexpected for more men to present to a forensic setting for treatment in support of challenging behaviours. For example a review undertaken by the Department of Health of assessment and treatment units for people with intellectual disabilities, identified that on average, 71% of patients were male. This percentage increased in relation to the security level of the unit (general wards, 65%, low secure 72%, medium secure 84% and high secure 88%) (Glover & Olson, 2010, p.14).

Five of the articles reported intellectual disability classifications. Lew and colleagues in 2006 reported a sample of eight, seven individuals with mild ID and one with a moderate ID. Alongside this, participants had additional diagnosis of clinical mental illness and in some cases presentations indicated symptoms that met more than one diagnostic criteria. Three had a diagnosis of major depression, two had a diagnosis of schizoaffective disorder, five had a diagnosed personality disorder and all were on psychiatric medication (Lew et al, 2006). Sakdalan and colleagues reported in a sample of 6 participants a mean IQ of 57.13 with a SD of 8.16 representing mild to moderate intellectual disability (Sakdalan et al, 2010). Charlton and colleagues reported a sample of 19 adolescences aged between 12-16yrs old (information obtained verbally from the authors) described as having both ‘intellectual disabilities’ and ‘mental illnesses’ (Charlton & Dykstra, 2011); Morrissey and colleagues reported that all 25 participants met the diagnostic criteria for at least one personality disorder and additionally had problems with emotion or behavioural regulation (Morrissey & Ingamells, 2011). Nineteen participants made up the sample for Baillie and Slater (2014) and all were described as having severe emotion regulation problems with three having a diagnosis of BPD. The three participants in Sakdalan and Collier’s (2012) study were chosen from their original participant group due to their high risk of sexual recidivism and were noted to have a mild – moderate ID. Brown and colleagues reported that IQs for their sample ranged from 40 to 95, with 82.5% having an IQ of 70 or below. All participants had a history of severe problem behaviours. 95% had at least one Axis I disorder, such as BPD, mood disorders or anxiety disorders (Brown et al, 2013). Of the two participants in McNair et al’s (2015) study one was on the intellectual disability register, the

other had a suspected intellectual disability and both had a history of parasuicidal and self-injurious behaviours.

Five of the articles were from the UK, three from the USA and two from New Zealand. The ten samples included three from forensic settings (31 participants), one from a service for adolescents (19 participants) and four from community settings (34 participants). Brown provided information for 27 participants; eleven were inpatients in a psychiatric hospital, eleven were in out-of-state residential treatment and 5 were in forensic settings (Brown et al, 2013). Sakdalan provided information on ethnicity for six participants four were New Zealand European, one Maori and one Pacific Islander (Sakdalan et al, 2010). The three participants selected for their 2012 study were New Zealand European and the third was of European and Maori descent (Sakdalan & Collier, 2012). There was no overall consistency in reporting the characteristics of participants.

The articles and book chapters describe small, unmatched population samples DBT with little demographic information and only Morrissey and Ingamells (2011) had a control group. The lack in general demographic reporting hinders the possibility of replicating the studies and consequently reduces the ability to assess potential generalisability. None employed a randomised control trial (RCT) design significantly increasing the difficulty in making comparisons between studies due to the variability in settings, treatment approach, evaluation measures and populations as outlined above (Klien & Miller, 2011).

With the exception of Brown et al (2013) any training that staff had received in the application of DBT was not made clear and supervision as described was variable and inconsistent. For Brown's study the clinical team was led by a licensed clinical social worker, who was themselves a DBT trainer and two clinicians intensively trained in DBT. They received weekly supervision and participated in a weekly consultation team, following DBT protocols. As Miller, Rathus and Linehan (2007) stated; training and regular supervision are integral to the delivery of DBT and therapists require enhanced capabilities to provide the requisite support (therapy for the therapists) to this high-risk population. Therefore the lack of detail regarding training and supervision adds to the difficulty in making comparisons between studies. In addition none of the articles or book chapters reviewed compared DBT to alternative approaches such as different therapeutic or group approaches.

Only Lew et al (2006) make mention of confounding variables such as medication. The effectiveness of medication in reducing many of the symptoms that co-occur with suicidal and self-harming behaviour, such as anxiety and depression has been well documented, (Bridge, Ivengar, Salary, Barbe, Birmaher, & Pincus, 2007). Therefore its use needs to be reduced or controlled, for example using a non-medication control group in order to reduce the potential for this to be a confounding variable.

Although all articles and book chapters refer to the simplification of the educational materials used, no mention is made as to how these materials were developed, piloted or evaluated.

The variation of presentation referred to in these samples is a common feature across them all. This is not surprising given that all samples are drawn from individual clinical settings with small populations. This also highlights the difficulties with making a diagnosis of BPD as a likely consequence of diagnostic overshadowing and delayed development of personality maturation as previously discussed (Moreland et al, 2008). Whilst, given this, it is not possible to evidence that DBT is an effective treatment for BPD in a ID population evidence can be provided to indicate effectiveness for ID clients with a range of mental health difficulties

5 DBT Services

5.1 Modes of treatment

As previously described, DBT borrows from Zen and is a ‘principle-driven treatment’ flexibly applied. The principles are equally applicable to the service providers as well as the recipients of the service. This leads to a wide diversity in service delivery models.

All of the articles and book chapters described DBT services providing 1-1 therapy with the exception of Sakdalan et al (2010) and Hall et al (2013) where participants received a skills group training program. It should be noted that Baillie, Slater, Millington, Webb, Keating and Akroyd (2010) divided participants into two groups, those described as receiving a ‘full service’ which included 1-1 therapy and a second group who received a skills group only. The full service group consisted of individuals that met full diagnostic criteria for BPD, the skills group consisted of participants described by the authors as not meeting the criteria for BPD but as presenting “with obvious emotion regulation difficulties” (Baillie et al, 2010, p18).

All participants received skills group intervention, however, the structure of these groups varied significantly. For example, Lew (2011) described a skills group cycle as 23 weeks long with each group session lasting two hours. Sakdalan et al (2010) described an “Adapted DBT Coping Skills Training program”; this was a thirteen week group program with each group lasting 1.5 hours. Carers participated in these groups alongside their clients. In their 2012 follow up, Sakdalan & Collier ran a seven month programme consisting on two hour weekly group sessions and an hour weekly of individual therapy. Charlton and Dykstra (2011) described skills training groups delivered twice a week for between 30-60 minutes rather than in a single 90+ minute’s session. Verhoeven (2010) described a service milieu that allowed individuals to opt out of a skills group if the attendance would be likely to provoke anxiety, dissociation or emotion dysregulation to such a degree that it would prevent learning. Brown et al (2013) describe a study lasting four years but it is unclear at which point the DBT intervention began.

Team consultation and treatment to the environment were described by the majority with the exceptions of Sakdalan et al (2010), Sakdalan and Collier (2012), Hall, Craven and Woodrow (2013) and McNair et al (2015) who gave no information as to whether team consultation or consultation to carers were provided in order to structure the environment. A significant proportion of the treatment to the environment described was delivered through carer’s involvement. This form of input varied significantly dependent on local resources and program design. For example Lew et al (2006); Charlton and Dykstra (2011) and Verhoeven (2010) describe carers participating in skills groups alongside their clients and Baillie et al (2010) describes a separate carers group that ran parallel to the clients’ skills group. Brown et al (2013) mention that in DBT-SS (an adapted DBT programme) support staff are offered monthly skills

system training. However, they fail to clarify whether they offered this to the support staff of participants in their study. Telephone consultation was provided by Baillie et al (2010) and Charlton and Dykstra (2011) only.

5.2 Evaluation Methods

Effectiveness was examined across all articles and book chapters using a variety of methods including client and carer completed questionnaires, repertory grid techniques, thematic analysis, the presentation of descriptive data and the inclusion of anecdotal evidence. There was no consistency in the use of evaluation tools; with Baillie et al (2010) suggesting that identifying appropriate assessment measures for this population presents a particular challenge. These authors hypothesised that most DBT behavioural indices that are measured by standard tools for example, number of suicide attempts, are not relevant to most individuals with an intellectual disability “because the base rate of these behaviours is close to zero” (Baillie et al, 2010 p19). Baillie and Slater (2014) have supported this hypothesis in describing a three year history of the evaluation and the assessment tools used with comments on their utility. The Symptom Checklist-90-Revised (SCL-90-R) (Derogatis, 1992) used for the first intake of clients to the Skills Group is offered as an example. The authors reported that the numerous adaptations to item wording required for an ID population, has compromised statistical and clinical utility and consequently its use has been discontinued for evaluation purposes. Following a review of the data these authors further suggested that HoNOS-LD (Wing, Curtis & Beavor, 1996) lacked the sufficient sensitivity to measure psychological change, consequently its use was discontinued for evaluation purposes. It is common practice for generic tools to be adapted for the ID population or new tools to be developed as demonstrated by the following examples.

With the exceptions of Verhoeven (2010), Sakdalan and Collier (2012), Brown et al (2013), Hall et al (2013) and McNair et al (2015) all authors administered carer completed questionnaires. Morrissey and Ingamells (2011) administered a client completed questionnaire and Sakdalan and Collier (2012) completed a number of client completed assessments. Brown et al (2013) measured incidences of challenging behaviour using records of the residential support provider and clinical records, which were then categorised into three levels of severity. In McNair et al's (2015) study repertory grid techniques were used which showed changes in construing, self-esteem and dilemmas about self. In response to the apparent lack of suitable assessment tools a number of the authors developed their own. Lew et al adapted the Youth Risk Behaviour Survey using 22 of the 87 items to develop a tool called the 'Risk Behaviour Survey' (2006). In Sakdalan et al (2010) group facilitators developed a 9-item questionnaire to assess learning as a result of undertaking the course and referred to this as the 'DBT assessment'. Morrissey described the development of a goal attainment scales for each of the skills modules and Baillie and Slater (2014) developed their own eighteen item psychometric measure (the DBT Carers' Feedback Questionnaire; DBTCFQ). The DBTCFQ measures carer perceptions of the extent to which the client had used DBT skills (Mindfulness, interpersonal effectiveness, emotion regulation and distress tolerance) over the previous four weeks.

Various forms of descriptive data were examined. For example, Sakdalan et al (2010) reviewed 'Incident Reports' and participant completed feedback forms, Charlton and Dykstra (2011) extracted information from 'diary cards'. Descriptive data was collected by Hall et al (2013) using audio-recorded semi-structured interviews. Treatment outcomes in the form of changes to

the environment were also reported by Charlton and Dykstra (2011) and Morrissey and Ingamells (2011) and, in the latter case, a control group was introduced. Morrissey and Ingamells (2011) reported outcomes for six participants, this cohort was then compared to a waiting list control group (n=5). It was identified that after 12 months the treated group members were more likely to move to low secure settings when compared to the control group (four out of six, compared to one out of five). Charlton and Dykstra (2011) also reported changes to behaviour in respect of the participants' use of DBT language, their demonstration of taught DBT skills. Insightfulness into emotions, thoughts and 'maladaptive' behaviour were observed, recorded and presented by the authors as evidence of the effectiveness of DBT. Anecdotal evidence was presented Baillie and Slater (2014) and Verhoeven (2010). For example "the most dramatic improvements I have seen are in cases of serious self-injurious behaviour reduced from several times a month to none over a period of months" (Verhoeven, 2010, p.334).

5.3 Evaluation Results

Each of the authors has used different psychometric tools to evaluate their service and in most cases developed their own assessment tool (Lew et al, 2006; Morrissey & Ingamells 2011; Sakdalan et al, 2010; Baillie & Slater, 2014). Only Baillie and Slater (2014) reported a pilot and evaluation of their assessment questionnaire. Most of the assessment tools were carer completed only and the user perspective was not sought, apart from Hall et al who used thematic analysis to "explore whether or not individuals felt that DBT programme helped them to better manage emotions and difficult situations" (2013, p.8). Four themes were identified 'Good things about the group', 'Bad things about the group', 'After the group' and 'In the future'. Hall et al (2013) reported that participants described a number of positive outcomes including feeling more in control of their emotions and being better able to deal with difficult situations. However it should

be acknowledged that across these studies the use of multiple measures supported the validity of data obtained (Becker, Hagenberg, Roessner, Woerner, & Rothenberger, 2004).

Sakdalan et al (2010) used carer completed questionnaires to undertake pre and post measures and overall noted improvements across all outcome measures. Significant differences were found for the Short-Term Assessment of Risk and Treatability (START), (Webster, Martin, Brink, Nicholls, & Middleton, 2004) and the Health of the Nation Outcome Scales for people with intellectual disabilities (HONOS-LD), however the differences observed for the Vineland Adaptive Behaviour Scale-Second Edition (VABS-II), (Sparrow, Balla, & Cicchetti, 2005) were not significant.

Morrissey and Ingamells (2011) reported significant reductions in distress and symptoms on the Global Severity of Distress Scale and the Brief Symptoms Inventory. Lew et al (2006) reported an increase in risky behaviours at 6 months, however, at the 12 month follow up risky behaviours were reported to have significantly decreased from the baseline. This reported reduction in risky behaviour was maintained at the 18 month follow up. The researchers suggested that these findings were likely due to the process of clients experiencing trauma in the process of acquiring the skills needed to deal with emotion. As the time for skill acquisition is lengthier for an ID population this represents a worsening of behaviour during the process of acquisition with improvement becoming evident at the 12 month stage. Charlton and Dykstra (2011) extracted information categorised as 'action items' for example; 'argued', 'tried to hurt self' etc., from diary cards. The relationship between the 'mean action items composite' and time was reported and indicated a significant reduction of action items over an 18 month period.

Sakdalan and Collier (2012) administered the SVR-20, which measures sexual violence risk, both before and after intervention and then again at a one year follow up. All participants showed a reduction in sexual violence risk. Marked improvement was also seen across a number of other measures relating to sexual awareness, victim empathy and attitudes that condone or support sexual offending. Information regarding incidents was collected from clinical notes and, although there was an initial increase in sexually abusive behaviours whilst they were taking part in the group, all incidents, including verbal and physical aggression were decreased after the completion of the group.

McNair et al (2015) completed repertory grids with two participants prior to and following treatment. Following the treatment one participant showed a marked improvement in self-esteem. The participant's construing of her ideal self remained the same as it was prior to treatment but she now saw herself as closer to it. The first participant had three implicative dilemmas which were resolved during the treatment. The second participant continued to have low self-esteem following treatment and developed three implicative dilemmas that she did not hold previously. This participant had poor attendance and maintained a high rate of self harming throughout the treatment.

Brown et al's (2013) study saw large reductions in problem behaviours during treatment which were significant across all three types of severity. The majority of improvement took place within the first year of treatment but the more severe behaviours improved more slowly. They identified BPD, self-injury and aggression as predictors of better outcomes. Intermittent

Explosive Disorder was identified as a reliable predictor of slower progress and smaller reductions in problematic behaviours.

Without exception all describe adaptations to the DBT model as outlined by Linehan (1993), with these adaptations presented as essential for an intellectual disability population. Brown et al (2013) used their own adaptation of the DBT model; the Skills System or DBT-SS. This samples standard DBT modules but significantly modifies the language and format to suit the needs of individuals with intellectual disability.

All studies included involved the principle of simplification with regard to the language, concepts and materials used in individual therapy and skills group. For example diary cards typically used in DBT were adapted to include pictorial cues. The skills group were supported in the learning process by developing ‘fun’ and ‘user friendly’ activities that engaged all sensory modalities through the use of media such as film, music, pictures and tactile activities.

The degree and intensity of carer involvement to support treatment to the environment also appears to be a significant clinical requirement when working with this population. Examples include Baillie et al (2011); Baillie and Slater (2014) who argue that a separate carer group is required to ensure carers are skilled sufficiently. Lew et al (2006) provided an example of care givers involvement in the learning process for clients. This was by providing additional support to the client through a therapist/client telephone consultation process of coaching during crisis situations. Charlton and Dykstra (2011) recommended that caregivers participate in the skills

group with their clients in order to learn and practice the skills being taught, to enable them to act as coaches for the students and to support learning.

General adaptations to the DBT model have also been described. For example Lew et al (2006) suggested that extended treatment, time and multiple repetitions are required to ensure that the largely cognitively based treatment approaches are simplified and taught. Morrissey and Ingamells comment that the delivery of a skills group over an 18 month period was “at least twice that typical of a standard program” (2011, p.13). Sakdalan et al (2010) described an adaption regarding the order of the treatment hierarchy. In conclusion any service development, for individuals with an intellectual disability, must allow for extended treatment times, significant simplification of materials and therapeutic processes and include carer involvement.

5.4 Articles/Book Chapters Conclusions

The effectiveness of DBT with individuals with intellectual disabilities was examined by all the authors and all argued that DBT is an effective intervention for this population. However these conclusions are relatively circumspect and couched in language that reflects the lack of hard evidence. For example Charlton and Dykstra concluded that data was “suggestive, but not in any way conclusive, regarding the effectiveness of DBT-SP” (2011, p.31) and Morrissey and Ingamells concluded that: “adapted DBT [is a] feasible and promising therapeutic approach” (2011, p.15). Sakdalan et al (2010) concluded that the findings of their pilot study ‘supported the concept’ of a skills group program as potentially a stand-alone therapeutic intervention. Brown et al suggest that the findings “merit further studies with more rigorous methodologies” (Brown et al, 2013, p.297).

6. Discussion

6.1 Professional Implications

It is evident from the paucity of available literature, that carrying out research with this client population is challenging. In addition, the quality appraisal undertaken for this review identified an overall methodological rating of ‘weak’, highlighting the fact that the evidence put forward within the literature does not consist of blinded, randomised controlled trials (RCTs) and meta-analyses thereof. The heterogeneous nature of this population is among the reasons why RCTs within this client population are unlikely. For example; RCTs often rely on categorising participants using diagnosis and most service users do not fit these criteria (Westen, Thompson-Brenner & Noveotny, 2004), as also evidenced in this review. Additionally, drawing participants from the small population of adults with intellectual disability along with the diversity of service delivery and settings pose considerable difficulties in organising large RCTs. Obtaining evidence regarding effectiveness using this research methodology with this population therefore currently presents significant challenges.

The question remains whether DBT is an effective therapeutic approach for this population? A consistent view offered by all of the authors reviewed, even after acknowledging study weaknesses, was that DBT was an effective intervention for this population. If considered within the research paradigm of practice-based evidence, that is non-experimental research carried out ‘in naturalistic/routine clinical settings’ (Henton, 2012), these findings could be considered a rich stream of data that when combined with future experimental research would enable us to answer the effectiveness question for the ID population.

Additionally the lack of qualitative research, for example patient outcome measures, suggests that understanding about how DBT is experienced by those receiving this intervention is limited.

Consistency in use of outcome measures when assessing DBT for this population would facilitate comparisons between studies. In addition, the development of a manual program for adults with an intellectual disability would support consistency of delivery of the therapeutic intervention.

DBT was originally developed as an outpatient treatment for women with a diagnosis of borderline personality disorder, so it is noteworthy that at a minimum, 76 of the 100 participants described in this review were male. This suggests that DBT is equally effective for both men and women.

The increase in risky behaviours at 6 months reported by Lew et al (2006) should be considered when planning treatment. Carers and service providers should be alerted to the possibility of risky behaviour increasing before decreasing.

6.2 Critique of Review

This review can legitimately be subjected to a number of criticisms. For one thing, the exclusion/inclusion criteria may have excluded papers from the review that demonstrated important findings. Such exclusions include those papers that were not written in English, case studies and papers that were unpublished or were dissertations.

Due to the limited available literature concerning the delivery of DBT to adults with an intellectual disability it is difficult to compare how effective DBT is in comparison to other treatments and therapies.

In addition, the lack of a second researcher to examine the material and corroborate the findings could also potentially call into question the internal validity of this review.

7 Conclusion

DBT is a relatively new therapy for an intellectual disability population. The evidence to date regarding the effectiveness, is primarily derived from practiced-based research and is supportive of DBT, albeit with significant adaptations, as being an effective psychotherapy for this population. Future research specifically focusing on identifying and understanding the effective components of DBT for an ID population would be of particular benefit as this may enable the identification of new and the most helpful ID adaptations (reasonable adjustments).

Table 1. Database Search

<i>Database</i>	<i>Date of search</i>	<i>Key Words</i>	<i>Number of potential finds</i>	<i>Number of relevant finds</i>	<i>Limiters</i>
PsycINFO, PsycEXTRA and PsycArticles	31/05/2012 04/02/2016	Learning Disability, Intellectual Disability and Dialectical Behaviour Therapy	13		English; Adult;
Medline	31/05/2012 04/02/2016	Intellectual Disability, Learning Disability and Dialectical Behaviour therapy	1	Verhoeven	English
The BPS (Professional Society)	31/05/2012 04/02/2016	Intellectual Disability, Learning Disability and Dialectical Behaviour Therapy	2		None Applied
Web of Science	12/06/2012 04/02/2016	Intellectual Disability, Learning Disability and Dialectical Behaviour therapy	2	Sakdalan 2010 Verhoeven 2006	English
Scopus	12/06/2012 04/02/2016	Intellectual Disability, Learning Disability and Dialectical Behaviour therapy	3	Sakdalan 2010 Lew et al Bertelli 2010	None Applied
Social Care Online	12/06/2012 04/02/2016	Intellectual Disability, Learning Disability and Dialectical Behaviour therapy	1	Sakdalan 2010	None Applied

Table 2. Journal articles identified

<i>ID code, Author (s), Country</i>	<i>Title of Article</i>	<i>Aims of Article</i>	<i>Participants, Measures</i>	<i>Conclusions</i>
1. Lew, Matta, Tripp-Tebo, & Watts (2006) USA	DBT for individuals with ID: A program description.	To describe an adapted DBT program for individuals with ID and to evaluate whether skills training within DBT is sufficient to induce observable improvement in people with BPD compared with standard group therapy (SGT).	8 individuals with ID (7 with Mild ID and 1 with Moderate ID). 5 of the 8 had a diagnosis of PD. All 8 were identified as 'multi-problem individuals who were risks in the community' Measure: RBS	The RBS (adapted version of the Youth Risk Behaviour Survey) need reference measured an increase in risky behaviours after 6 months, followed by a significant decrease from the original base line after 12 months. Clinical Commentary: preliminary results "point to its efficacy for ID individuals who have problems with emotion regulation" and adapting the DBT model is essential for an ID population.
2. Baillie, Slater, Millington, Webb, Keating & Akroyd (2010) UK	What it takes to set up a DBT service for adults with a learning disability: the lessons so far.	To describe what is needed to set up a DBT service for adults with an intellectual disability and the lessons learnt from this experience.	Eight members of a DBT team consisting of both health and social care staff. That is 3 psychologists, 3 nurses and 2 social workers.	1. Identify a need for the service. 2. Consult with commissioners and senior managers. 3. Ensure financial commitment is in place. 4. Identify a minimum number of clinical staff. 5. Ensure the clinical staffs identified have protected time. 6. Ensure that supervision is available from an experienced DBT practitioner. 7. Network with existing LD DBT providers.
3. Sakdalan, Shaw, & Collier (2010) New Zealand	Staying in the here and now: A pilot study of the use of DBT group skills training for forensic clients	To evaluate the effectiveness of a DBT group skills training program that has been adapted for offenders with ID.	Seven male and two female clients (mean age 26.18; SD 2.92) With a mean IQ of 57.17; SD 8.56. All had prior charges	Improvements were noted across all outcomes measures based on the result of the pre and post-assessment. The START risk and strength domains and the HONOS-LD were found to be significant while the VABS-II was found non-significant. The participants' achievement on the DBT assessment was described as relatively high.

	with ID.		and/or convictions for violent crimes. Measures: START; VABBS-II; HoNOS-LD; Incident reports; DBT assessment (9-item questionnaire).	Discussion: These authors suggest that the pilot study demonstrates that the DBT group skills training program format has the potential to be used as a stand-alone intervention.
4. Charlton (2011) USA	DBT for special populations: treatment with adolescents and their care givers.	Preliminary findings were presented regarding adaptations made to DBT when working with populations who have both intellectual disabilities and mental illnesses.	Pilot Study: Conducted with 19 adolescents aged 12-16yrs old in a day treatment program.	Identifies a number of issues that must be addressed when providing psychotherapy to individuals with intellectual disabilities and mental illnesses. The authors suggest that DBT is an effective psychotherapeutic technique for individuals with ID.
5. Morrissey & Ingamells (2011) UK	Adapted dialectical behaviour therapy for male offenders with intellectual disability in a high secure environment: six years on.	Describes the rationale for the development of an adapted DBT program for men with mild disabilities, how it evolved over a 6 year period, the modifications to mainstream DBT and the challenges which remain.	25 patients all met diagnostic criteria for at least one personality disorder and had problems with emotional and behavioural regulation Measures used MCAMS- R, EPS, S-TAEI, and ASIT. No findings reported yet.	Conclusions were based on anecdotal evidence; 1) 'Promising' initial findings for a forensic LD population. 2) Adaption of DBT manual is necessary. 3) Training of wider team and receiving services is necessary. 4) Clinical experience of patients increasing ability to 'express feelings in more adaptive way. Resulting in reduced seriousness of self-harm incidents and interpersonal aggression.
6. Baillie & Slater (2014)	Community DBT as a means of engaging	"Operational issues are reviewed for example 'the optimal size of skills	Nineteen clients who have been seen by DBT service during the first	Conclusions are based primarily on anecdotal evidence; 1) There is a clear rationale for providing DBT to

UK	positively with challenging behaviour in adults with an intellectual disability	training groups, the need for a carers' group, the challenge of clients with intellectual disabilities developing genuine commitment to the therapeutic process'.	two years of its operation are described. 11 males;; 3 met the criteria for BPD; 19 with severe emotion regulation problems; 9 suicidal or para-suicidal behaviour; 5 were a risk to self 13 were verbal or physically aggressive 4 were on the Autism spectrum;	an intellectual disability population. 2) DBT requires considerable time commitment from all members of the DBT team, and sustained support from senior service managers. 3) DBT enables us to provide a specialist health service to people with an intellectual disability who present chronic and complex challenges to services that support them. 4) Anecdotal and psychometric evidence indicates clients are developing their emotion regulation and distress tolerance skills 5) There is a need to collect significantly more data to create a comprehensive picture of both therapeutic process and outcomes. 6) Developing measures suitable for an intellectual disability population is a particular challenge.
7. Sakdalan & Collier (2012) New Zealand	Piloting an evidence-based group treatment programme for high risk sex offenders with ID in the NZ setting	To run a pilot study of an adapted sex offender treatment programme based on an earlier (2010) study.	3 male participants, rated as mild- moderate ID, chosen from sample of initial pilot study (2010). Selected due to high risk of sexual recidivism. Measured sexual violence risk before and after intervention and at 1 year follow up.	All participants showed a reduction in risk of sexual violence. Marked improvement in other measures relating to sexual awareness, victim empathy and attitudes that condone sexual offending. A reduction in verbal and physical aggression.
8. Brown, Brown & Dibiasio (2013)	Treating individuals with ID and	To examine whether individuals with ID would show reduction in	40 participants with developmental disabilities- 82% with	Significant reductions in all three behaviour categories in the first year and maintained over 4 years. A 76% reduction in serious behaviours

USA	challenging behaviours with adapted DBT	challenging behaviours while receiving standard individual DBT in conjunction with the skills system (DBT-SS).	ID and 18% with autism- histories of aggression and other challenging behaviours Changes in behaviour monitored over 4 years using behavioural treatment plans that consisted of 'red flags', 'dangerous situations' or 'lapse behaviours'. Some participants didn't have plans so incidents were graded retrospectively. Analysed on average 6.9 years of data.	(violence, self-injurious and illegal behaviours) over 4 years. Couldn't conclusively attribute changes to DBT as no control group. DBT valuable as a long term comprehensive treatment.
9. Hall, Craven & Woodrow (2013) UK	People with learning disabilities experiences of a Dialectical Behaviour Therapy Skills Group: A Thematic analysis.	To use thematic analysis to 'explore whether or not individuals felt that DBT programme helped them to better manage emotions and difficult situations'.	5 participants with ID Both qualitative and quantitative methods used. Thematic analysis of semi-structured interviews Quantitative measures used GDS, GAS & CAMS-R.	Four themes identified 'Good things about the group', 'Bad things about the group', 'After the group' and 'In the future'. Hall (2013) reported that participants described a number of positive outcomes including feeling more in control of their emotions and being better able to deal with difficult situations. Initial quantitative findings described as 'promising'
10. McNair, Woodrow & Hare (2015)	Using repertory grid techniques to measure change	To examine the psychological changes that occur in DBT through changes in self-esteem,	Case studies of 2 individuals- 1 only had 'suspected ID' Used repertory grid	'Sarah' (participant with LD) demonstrated significant improvement in self-esteem following DBT.

UK	following dialectical behaviour therapy with adults with LD: two case studies.	change in construing and changes in dilemmas about themselves	techniques to assess changes in construing, self-esteem and change in dilemmas.	
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Table 3. Book Chapters Identified

<i>Author (s), Country</i>	<i>Title of Chapter</i>	<i>Aims of Chapter</i>	<i>Conclusions</i>
1. Lew (2011) USA	DBT for adults who have ID.	The chapter explores the rationale for using DBT with an ID population; adaptations required and critically reflects on its effectiveness in practice.	
2. Verhoeven (2010) New Zealand	Journeying to wise mind: DBT and offenders with ID.	This chapter considers and criticises a number of issues regarding the complexity of diagnosing personality disorder for individuals with intellectual disability. It then makes a case for the use of DBT to treat sex offenders with intellectual disabilities describing a service model 'Journeying to Wise Mind program'.	The author argues 'that there is merit in DBT for people with ID' that it is effective in reducing emotional dysregulation and behaviours such as physical aggression and self-injurious behaviour.
3. Charlton & Dykstra (2011) USA	DBT for special populations: Treatment with adolescents and their caregivers.	The chapter describes preliminary findings regarding the types of adaptations made to DBT and their effectiveness in working with a population who have both intellectual disabilities and mental illnesses.	

Table 4. Quality Appraisal

<i>Study</i>	<i>Study Design</i>	<i>Confounders</i>	<i>Blinding</i>	<i>Data Collection</i>	<i>Withdrawals & dropouts</i>	<i>Overall rating</i>
1. Lew, Matta, Tripp-Tebo, & Watts (2006)	Weak	Weak	Weak	Weak	Weak	Weak
2. Baillie, Slater, Millington, Webb, Keating & Akroyd (2010)	Weak	Weak	Weak	Weak	Weak	Weak
3. Sakdalan, Shaw, & Collier (2010)	Weak	Weak	Weak	Moderate	Weak	Weak
4. Charlton (2011)	Weak	Weak	Weak	Weak	Weak	Weak
5. Morrissey & Ingamells (2011)	Moderate	Weak	Weak	Moderate	Weak	Weak
6. Baillie & Slater (2014)	Weak	Weak	Weak	Weak	Weak	Weak
7. Sakdalan & Collier (2012)	Weak	Weak	Weak	Weak	Weak	Weak
8. Brown, Brown & Dibiasio (2013)	Weak	Weak	Weak	Weak	Weak	Weak
9. Hall, Craven & Woodrow (2013)	Weak	Weak	Weak	Moderate	Weak	Weak
10. McNair, Woodrow & Hare (2015)	Weak	Weak	Weak	Weak	Weak	Weak

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Section Two: Research Report

Developing an Understanding of the Impact of DBT on Adults with an Intellectual Disability with Emotion Regulation Difficulties

Abstract

Introduction: The current study explored the experiences of adults with intellectual disabilities (ID) receiving Dialectical Behaviour Therapy (DBT), their direct carer's experiences of participating in a DBT carers group and the experiences of the therapists delivering these services in the community.

Method: Three focus groups (client; carer and therapist) were run, each focus group session was recorded and then transcribed and analyzed using Interpretative Phenomenological Analysis (IPA) which allowed for an examination of the personal meaning and sense-making of those individuals attending and providing a DBT service.

Results: The experience of participating in a DBT service for both clients and therapists is emotionally challenging. Anecdotal evidence of the effectiveness of DBT is provided and additionally suggests that as a consequence of participation in a DBT service, there is an increase in confidence and maturation of therapeutic skills for both therapists and carers.

Conclusion: The clinical implications described are supportive of the use of DBT with an ID client population and provides rationale for the further development of services.

1 Introduction

A significant body of evidence exists suggesting that people with an intellectual disability are at greater risk of developing mental health problems than the general population (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Deb, Thomas & Bright 2008; Hatton, 2002). Epidemiological studies report that between 30% and 50% of individuals with intellectual disabilities meet the minimum diagnostic criteria for at least one mental health problem (Bouras & Holt, 2004; Cooper et al, 2007; Smiley, 2005). Personality disorder is estimated to range from 2% to 9.1% (World Health Organization, 1993; American Psychiatric Association (APA), 1994) to 9.1% with specific prevalence rates for borderline personality disorder estimated at 1.4% in the general population.

Within the intellectual disability population personality disorders represent a significant proportion of reported mental health difficulties with prevalence rates ranging from 1% (Deb & Hunter, 1991) to 91% in community settings (Whitaker, & Read, 2006; Naik, Gangadharan, & Alexander, 2002; Khan, Cowan, & Roy, 1997). A critique of these findings in the review carried out by the researcher suggests that these rates need to be viewed with caution. However, there is no doubt that there are a high number of individuals with ID who experience psychological distress.

A range of psychological therapies have been found to be effective in supporting individuals with intellectual disability (Brown, Duff, Karatzias, & Horsburgh, 2011). A clear mandate is provided in the NICE clinical practice guideline 78 issued in 2009, in the use of Dialectical Behaviour Therapy (DBT) for individuals with an intellectual disabilities and a diagnosis of personality disorder (see review section 2.2 for details). It should be noted however that the review of psychological therapies carried out by Brown et al (2011) did not include DBT due to

a paucity of literature.

1.1 What is DBT?

DBT is a broad-based cognitive-behavioral treatment, based on a dialectical and biosocial theory of psychological disorder placing a significant emphasis on an inability to regulate one's emotions and behaviours with regard to both under and over control of these traits (Linehan, 2015).

1.2 Treatment Functions

DBT identifies five treatment functions:

- (1) To develop the individuals capability by increasing skillful behaviour with regard to emotion regulation.
- (2) To maintain and increase the participants motivation to change their behaviour and to engage with treatment.
- (3) To support the generalization of change through treatment.
- (4) To maintain and increase the therapist motivation to deliver effective treatment.
- (5) To enable the individual to restructure or change his or her environment in such a way as to support and maintain momentum and progress towards goal attainment. (Linehan, 2015).

1.3 Treatment Modes

In order to deliver against these functional goals, the treatment components are divided into a variety of modes. The modes of treatment include weekly one-to-one therapy, skills training in groups (in mindfulness, distress tolerance, emotion regulation and interpersonal effectiveness),

peer supervision (Consultation Group), telephone consultation in which the therapist offers skills coaching to the patient outside of treatment sessions and strategies for treatment to the environment (Linehan, 1993).

1.4 Treatment Process

DBT was originally developed to address and reduce rates of suicidality and self-harm through a strong internal structure with core manuals and protocols for treatment (Linehan, 1993). It assumes that those individuals that engage in suicidality and self-harm lack the necessary interpersonal and self-regulation skills to manage their emotions. In addition environmental and personal factors inhibit the use of any existing positive behavioural skills the individual may have and/or reinforces the use of less helpful ones.

Based on these assumptions clients are encouraged to acknowledge and accept painful emotional experiences using taught skills such as radical acceptance and mindfulness during therapy. Other skills are taught to prevent or push away their negative emotions. In parallel the clients attend group skills training to help them to implement change. Additional support is available in the form of telephone coaching should clients wish to discuss their use of DBT skills between sessions.

1.5 Effectiveness of DBT

DBT has been shown to lead to reductions in hospitalisation, increased therapy retention rates and lower risk of suicide (Binks et al., 2006; Bornovalova & Daughters, 2007; Feigenbaum, 2007; Martens, 2005). In a review of the literature carried out by the researcher evidence regarding the effectiveness of DBT with an ID population was identified albeit with significant adaptations to the DBT model. All papers reviewed specifically recommended that future

research with focus on identifying and understanding effective components of DBT for an ID population would be particularly beneficial in enabling the identification of new and necessary ID adaptations (reasonable adjustments). Studies providing data about client experience can provide insight into the effective components of psychological therapies. The data can also be used to explore the factors that effect change (Hodgetts & Wright, 2007). This is of particular importance to the ID population where this has been given less attention. The current research explored the subjective experiences of adults with ID and their direct carers receiving DBT and their therapists delivering these services.

1.6 Qualitative Research on DBT

Although a significant number of studies have examined the effectiveness of DBT (Feigenbaum, Fonagy Pilling, Jones, Wildgoose & Beddington, 2012; Neacsiu & Linehan, 2014; Valentine, Bankoff, Poulin, Reidler & Pantalone, 2014) for a general population, relatively few published qualitative studies have been carried out. Research examining patient and therapist perceptions of the use of DBT in treating suicidal and self-harming behaviour analysed using grounded theory identified a number of themes. Emergent themes from a client perspective included *'therapy is life-saving'*, *'therapy provides skills to conquer self-harm urges'* and *'therapy helps acceptance of own feelings'*. The views of therapists on the whole were concordant with the clients. A self-critique by the researchers highlighted that the interviews were held on the premises on which the DBT service was provided. The concern was that clients may have had an underlying fear that unfavorable response might impact on their future treatment options (Perseius, Ojehagen, Ekdahl, Asberg and Samuelsson, 2003).

Hall et al (2013) used thematic analysis to examine clients' own understanding about effectiveness of DBT, and why this might be, and identified three major themes. The first theme concerned the therapeutic relationship. This was particularly emphasized by those participants who were positive about DBT; using such phrases as 'non-judgmental' and 'validating'. Secondly, applying the taught skills to everyday life is difficult. Finally, that DBT had allowed clients to gain greater control over their emotions and had reduced impulsive behaviours. A critique of this research highlighted that many participants of the study had not completed a full cycle of the DBT and questioned whether participants had sufficient experience of the model to judge its effectiveness (Cunningham, Wolbert and Lillie, 2003).

A further study examined patient experiences of DBT and its impact on their lives using Interpretative Phenomenological Analysis (IPA). Three major themes emerged. The first focused on the experience of 'joining' a DBT programme. The focus of the second theme was the 'experience' of DBT (for example the experience of a therapeutic relationship with a therapist). The focus of the third theme was the 'evaluation' of the experience. The Client referred to the positive impact of DBT but acknowledged that a significant contribution to this was the result of the additional work that they had engaged in outside of the sessions. The researcher highlighted that many of the participants had received the implicit message that DBT was the only treatment that would offer them any benefit and therefore their perception was that they had little choice in services available to them. A criticism of this research was that many of the participants were interviewed following a significant period after completing the DBT programme (up to 12 months). This delay may have affected memory resulting in a change in participant's memories (Wright and Gough, 2007).

A further recent study carried out with adults with ID analysed data collected using thematic

analysis to explore whether attending a DBT group resulted in the participants feeling that they were better able to manage their emotions and difficult situations. Four themes were identified ‘Good things about the group’; ‘Bad things about the group’; ‘After the group’ & ‘In the future’. Although the results suggested that the participants were generally positive about the experience of attending DBT a number criticism were made about the service. As a consequence the researcher made a number of changes to the service model (Hall, Bork, Craven & Woodrow, 2013).

2 Method

2.1 Design

As the researcher was interested in the subjective and authentic experiences of the participants, a qualitative methodology was used. The method chosen was Interpretative Phenomenological Analysis (IPA) (Smith, 1996; Smith & Osborn, 2003) as this qualitative approach attempts to understand how an individual makes sense of what *happens* and the meaning of that *happening* (Smith, Flowers & Larkin, 2009). It was hoped that this approach would provide insight into clients’, carers’ and therapists’ experience of attending a DBT service. The data analysed in this research was obtained using focus group methodology.

2.2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis was selected as the method of analysis for this research as it allows for an examination of the personal meaning and sense-making of those individuals experiences of attending and providing a DBT service. Alternative methods of analysis were considered; such as grounded theory, content analysis, narrative psychology and

discursive psychology. The primary reason for using IPA was the fit with the nature of the research question, which focuses on personal meaning and sense making of participants experiences of DBT, and therefore was felt to be the most suitable form of analysis to understand the phenomena of attending a DBT service.

The alternatives to IPA tend to focus on the content of the speech only for coding purposes whereas IPA draws on the interpretation of the researcher to understand the deeper meanings of the participants' experiences of DBT. As the outcome of analysis is always the analysts' interpretation of the participants thinking and experience this is referred to as the 'double hermeneutic' within IPA (Smith, Flowers & Larkin, 2009).

2.3 Focus group

Although a number of methods to obtain qualitative data exist, focus group methodology was used as "the focus group presents a more natural environment than that of an individual interview because participants are influencing and influenced by others, just as they are in life" (Krueger & Casey, 2009, p.7). The researcher's clinical experience suggested that in order to get the depth of experiential reflection desired in a one off situation with individuals with ID it would be necessary for the participants to feel safe. As the participants had all been part of an original group, e.g. client, carer or therapist groups, and the environment in which the data was to be collected and the groups were to be held in the same building it was thought that this would help "to create to safe, supportive environment, where the participants felt comfortable sharing their experiences with each other" (Palmer, Larkin, De Visser & Fadden, 2010, p.118). Smith states "if the researcher is convinced that participants are able to discuss their own personal experiences in sufficient detail and intimacy, despite the presence of the group, then the data may

be suitable for IPA” (2004, p.50-51).

2.4 The Challenge to IPA of Focus Group Methodology

As stated by Smith in his seminal text, when discussing the use of focus groups to collect data “they may be less obviously suitable for IPA researchers, but they certainly been employed in published IPA work “(2009, p71). Examples include Dunne & Quayle (2002), O’Toole, Ohlsen, Taylor, Purvis, Walters & Pilowsky (2004) and Vandrevalla, Hampton, Daley, Arber & Thomas. (2006). However, the decision to use focus group methodology with IPA did present several challenges as the data collected would need to be analysed acknowledging the presence of “multiple voices, the complexity of the individual and shared contexts, and the interactional complexity of the discussion itself” (Palmer et al, 2010, p.100). That is, the accounts offered are likely to be shaped by the researcher’s questions, the degree of shared experience and reactions among the participants and the developing dynamic of the interaction itself. Smith notes this will involve approaching analysis “at least twice: once for the group patterns and dynamics and subsequently, for ideographic accounts” (2004, p.50). Additional challenges include the negotiation of part-whole relationships that is the ideographic versa group perspectives and ‘the management of the interplay between real-time discursive and post-hoc thematic sense making’ (Tomkins and Eatough, 2010, p.244).

IPA literature referring to analysis does not dictate any single approach to working with data; rather it suggests a set of principles to be applied flexibly depending on the analytic task (Reid, Flowers & Larkin, 2005). Palmer et al (2010) developed a comprehensive eight step analytical protocol for working with focus group data using IPA. The researcher decided to use an adapted version of this protocol which is described in the procedure for a number of reasons firstly the

data from the three focus groups was insufficiently homogeneous to be regarded as a single data set. Secondly there was insufficient data to justify the use of Palmer's model, and finally Palmer's research team capacity in relation to number of researchers was significantly larger number than my own capacity – single handed researcher.

2.5 Epistemological Position

The epistemological stance chosen for this research was a critical realistic perspective; it was selected for two principal reasons. Firstly, it fits well with IPA, the qualitative analysis approach used within this research, as IPA focuses on the meaning of experiences, perceptions and accounts of events rather than objective records. Secondly, the therapeutic approach being considered, DBT, uses Zen principles to support the client to increase their ability to accept themselves, the worlds they inhabit and change. The first of these principles is “the world is perfect in the sense that it is the best it can be” (Swales & Heard, 2009, p.43) meaning that the world is perfect as it is in this present moment. This principle aligns well with an epistemological position that assumes that reality exists and our perception of reality is shaped by subjectivity and social forces (Guba and Lincoln, 1994).

2.6 Researcher's Declaration of Interest and Experience

The researcher completed an intensive training course in dialectical behaviour therapy with the British Isles DBT training team in 2005 and has established and led two Intellectual Disability DBT services within the NHS. As a DBT clinician he has facilitated numerous skills groups, carers groups and provided one-to-one therapy to several individual clients. Additionally he has presented papers to the DBT national conference and co-authored and published two articles

concerned with the use of DBT with adults with ID. In 2011 he was awarded a post-graduate certificate in DBT from Bangor University.

As IPA analysis involves interpreting the meaning/s of the data collected, the researcher inevitably has drawn on his own experiences of participating in the DBT service. Throughout the analytic process the researcher felt that this personal experience allowed for deeper interpretations to occur. To support the analytic process and to capture the researcher's reflections a diary was maintained, allowing the researcher to consider the impact of his own experiences on the data analysis.

2.7 Clinical setting for research

In 2009 the community adult intellectual disability psychology service established a Dialectical Behaviour Therapy (DBT) service for adults with an intellectual disability. This service is offered to individuals with 'Mild' to 'Moderate' intellectual disabilities with severe emotion regulation difficulties who engage in risky behaviours such as suicidal or parasuicidal behaviours, self-harm, excessive consumption of alcohol, risky sexual behaviour or verbal or physical aggression. The service consists of weekly one-to-one therapy, skills training in groups, consultation group (peer supervision meetings) for therapists, carers skills groups for those supporting the attending adults with an intellectual disability and telephone consultation where therapists are available to provide 'coaching' outside of treatment sessions. All the therapists involved in the service have completed intensive training in DBT with the British Isles DBT training team and or a post graduate certificate in DBT.

A number of local adaptations have been made to the DBT treatment model. An example is the

development of a more structured carers group, which supported carers to both practice the skills being presented to the clients that week and to assist the person that they support to practice DBT skills in-between sessions. A more detailed discussion of how the carers group functions and an evaluation of its benefit can be found in Baillie and Slater (2011).

This service is fundamental to the countywide strategy for responding to behaviour that challenges in that it provides a differentiated response to challenging behaviour (Slater & Baillie, 2008; Slater & Baillie, 2011; Baillie & Slater, 2014). This has been achieved by providing different DBT service approaches based on the complexity of need. For clients with low to medium complexity needs a DBT skills group only is offered while for clients with high-complexity needs a full DBT treatment package is provided.

The length of time most clients remain in the first phase of treatment is significantly longer than typical services. The skills groups run continuously on a ten-week cycle for each module and currently are separated by a three-week break in between each module. The service identified that clients were failing to engage fully and had difficulty in understanding the key skills and ideas that they were being presented with. Consequently, for most of the clients, there has been the need to participate in at least two full cycles of the skills modules over a period of eighteen months before being able to grasp and implement the skills. As a result most clients have needed to attend the skills group for at least three full cycles (i.e. two and a quarter years) before clear benefits are demonstrated.

3 Participants

Three groups of participants were recruited to be involved in the focus groups: a client group, a carer group and a therapist group.

The client group was made up of three individuals with 'Mild' to 'Moderate' intellectual disabilities who had severe emotion regulation difficulties and engaged in risky behaviours such as suicidal or parasuicidal behaviours, self-harm, excessive consumption of alcohol, risky sexual behaviour or verbal or physical aggression. Clients were only included if they had participated in a DBT programme for a minimum of 6 months, i.e.; had attended a skills group and or received 1-1 therapy for at least a six month period. The carers group included four carers that had attended a carers group for a minimum of one year. The therapist group included six therapists who had facilitated either the skills or carers group for a minimum of one year and had delivered 1-1 therapy for a minimum of 6 months.

The tables below show the gender, ethnicity of the clients, carers and therapists and their time in the DBT groups:

Table 5: Client Demographics

Gender	Ethnicity	Time in DBT	Time in DBT 1-1	Time in Skills Group
Female	White British	12 months	6 months	11 months
Female	White British	41 months	15 months	39 months
Female	White British	40 months	40 months	23 months

Table 6: Carer Demographics

Gender	Ethnicity	Time in Carers Group
Male	White British	Over a 41 month period
Male	White British	Over a 41 month period
Female	White British	Over a 40 month period
Female	White British	Over a 40 month period

Table 7: Therapist Demographics

Gender	Ethnicity	Time in DBT service
Male	White British	Since 2008
Male	White British	Since 2008
Male	White British	Since 2008
Female	White British	Since 2008
Female	White British	Since 2008
Female	White British	Since 2008

4 Measures

4.1 Development of the focus questions

The focus group questions were designed to examine how clients, carers and facilitators experienced receiving and delivering DBT. A set of questions were developed for each focus group. All questions were open-ended and loosely structured in order to support participants to explore their experiences fully. In addition it was expected that additional questions and prompts would be required to support the generation of richer and more personal accounts. Examples of the topic guides for each of the three focus groups can be seen in appendix A.

5 Procedure

5.1 Ethical and research and development approval

All patients and carers participating in this research were either receiving or had received a service funded by the National Health Service (NHS); this necessitated the compliance with the ethical and governance arrangements for both the NHS Trust delivering the service and the NHS. The initial proposal was approved by service Research & Development lead for the Trust. On the 13th of September 2013 the service and the researcher were TUPE transferred from one NHS

Trust to an NHS Foundation Trust following NHS restructuring. As a consequence the researcher approached the trust's Research & Development manager and the research was again approved in principle with the trust giving agreement to sponsor the research. The proposal was also reviewed by the Health Research Authority; NRES Committee London – Brent in June 2013. In October 2013 following minor amendments, the research proposal was granted a favourable opinion. Copies of the Health Research Authority; NRES Committee London – Brent approval letter were sent to trust's Research & Development manager and management approval was granted in November 2013 (see Appendix B for copies of approval letters).

5.2 Recruitment and group process

Following an initial meeting with the field supervisor potential clients met with the field supervisor and a Speech and Language Therapist (SALT) one week prior to the planned focus group. During this meeting an information sheet was explained and discussed (see appendix C). When both the field supervisor and SALT were confident that the clients had fully understood the information, they were asked to think about their participation in the study and asked to inform the field supervisor of the outcome of their decision prior to the scheduled date of the focus group. All clients approached agreed to participate in the study.

The field supervisor approached both the carers and facilitators individually and provided information about the study and to request their consent as participants. All three focus groups were held at the Community Learning Disability Team's base in a quiet room. At the beginning of each focus group the participants were again provided with information and their consent obtained, to allow any of those who had previously consented to withdraw. Each group lasted between 45-60 minutes. At the end of each group all participants were asked if they had any

questions and or debriefing needs.

5.3 Transcription and data handling

In order to ensure familiarity with the data, the three focus groups recordings were transcribed by the researcher. All were transcribed verbatim, and to certify the validity and accuracy of the transcriptions, each group recording was listened to again whilst the transcripts were simultaneously read. Transcripts can be found in addendum A, B and C.

6 Data Analysis Theoretical Method

Data analysis and coding of the three focus group transcripts was conducted by integrating the principles outlined by Smith et al (2009) and Palmer et al (2010). IPA was originally described by Jonathan Smith in his 1996 paper and is typically used to analyse the data obtained from an individual via clinical interview (Smith 1996). The researcher considered that the most effective way to obtain the data desired was by using focus group methodology. This resulted in a considerably more complex interactional environment and therefore it was necessary to address this during data analysis. To this end the researcher used a model developed by Palmer et al (2010) (see table B below) to analyse focus group data using IPA.

6.1 Data Analysis Process

Smith et al (2009) propose a six step model. In step one the researcher is required to become immersed in the data to ensure that the participant becomes the focus of the analysis by reading and re-reading the transcripts. To ensure active engagement with the data the researcher read through each transcript and then re-read it, picking out noticed content. The researcher recorded this content verbatim in the right hand column of the transcript in red.

Step two involved examining the semantic content and the language used at a basic exploratory level making notes that were descriptive in nature and with a phenomenological focus and represented the participant explicitly as far as was possible. Language of note to the researcher was noted in blue ink. The researcher made interpretive notes, focusing on the language used and noted in green the context of these comments.

6.2 Translation of initial coding to themes

On completion of these first two steps the initial stage of coding each transcript was examined again and emergent themes identified. An example of this can be found in appendix D. The researcher used Braun and Clarke's definition of a theme when carrying out this third step in the process: "a theme captures something important about the data in relation to the research question, and represents some level of *patterned* response or meaning within the data set" (2006, p.82).

When examining the data for emergent themes the researcher made an analytic shift and started to work primarily with the initial notes rather than with the actual transcript. The themes identified contained "not only the participant's original words and thoughts but also the analyst's interpretation" (Smith et al, 2009, p.92). During this process the researcher's interpretations and understanding of the live experience of the participants, inevitably became integrated in the resulting analysis. The final product therefore, is a collaborative effort of both the participant and researcher. An example of this can be seen in appendix E. In order for the researcher to keep track of thoughts, observations, feelings and reflections reflective notes were maintained throughout the entire data analysis process.

The fourth step required the researcher to search for connections across the emergent themes

within each transcript, (Smith et al, 2009). The researcher produced a list of the themes in chronological order and then clustered them into related themes. As a result of this process smaller sub-themes emerged and these were grouped together to form larger superordinate themes.

Step five required the researcher to move from one focus group script to the next. The researcher was careful to treat each script separately and attempted to bracket the ideas identified before moving onto the next script so that each set of ideas were distinct.

Step six concerned identifying patterns across the focus group scripts. Throughout these six steps, the researcher applied the principles of the protocol developed by Palmer et al (2010) for using IPA with focus group data. To increase the reliability of the analysis, the researcher and his supervisor met to review the themes that had emerged, themes were revised following this meeting.

7 Results

Analysis of the three focus group transcripts resulted in the emergence of three super-ordinate themes: ‘change’, ‘it’s painful and ‘development’. These themes, made up of sub-ordinate themes taken from one or more of the focus groups, are a representation of the multi-perspective lived experience of those that participated in this research. The super-ordinate themes emerged following an integration of sub-ordinate themes with each of these sub-ordinate themes in turn being determined by the analysis of the identified themes arising from the focus groups. Exploration of these super-ordinate themes and their constituent sub-ordinate themes (see figure 2 overleaf) will form the basis of this results section. Each theme will be illustrated by verbatim extracts.

The themes identified were selected as being relevant to the research question. The author acknowledges that that they do not represent all aspects of the participant’s experience of attending a DBT service. Minor changes have been made to aid readability of the verbatim extracts. Brief hesitations, word repetitions and utterances such as “erm” have mostly been removed. All identifying information has been changed to protect the anonymity of participants.

Figure 2: Superordinate Themes

Super-ordinate theme: Change

<i>Sub-ordinate Themes</i>	<i>Transformation (client group)</i>	<i>Alteration to self (carers group)</i>	<i>Change (therapist group)</i>
Themes	Acceptance of Self	Change to self	Change Client
Themes	Skills Development	Insight	Change Therapist
Themes	Change is Possible		Change Service

Super-ordinate theme: It’s painful

<i>Sub-ordinate Themes</i>	<i>Unsupportive Environment (client group)</i>	<i>Emotional Pain (client group)</i>	<i>Personally Challenging (therapist group)</i>
Themes	Frustrations with Services	Shared Experience	Emotionally Challenging
Themes	Environmental change required	Emotions are dangerous	Cognitively Challenging
Themes	Powerlessness	Emotional Avoidance	Practically Challenging

Super-ordinate Theme: Development

<i>Sub-ordinate Themes</i>	<i>Personal Growth (carers group)</i>	<i>Personal Development (Therapist Group)</i>
Themes	Personal Awareness	Adaptability
Themes	Change of Practice	Reflective Practice
Themes	Insight into client	

Super-ordinate theme: Change

This theme includes sub-ordinate themes of ‘transformation’, ‘alteration of self’ and ‘change’ and their constituent themes. The theme refers primarily to changes in self over the time that individuals (clients, carers and therapists) who participated in the DBT service experienced. For each group the focus of these changes was somewhat different. Clients appeared primarily concerned with an idiosyncratic perspective, the carer focus was self-reflection and the perspective of the therapists was primarily concerned with a broader perspective of a whole system change.

Sub-ordinate theme, Client Group: Transformation

The sub-ordinate theme ‘transformation’, arising from the clients’ group, is primarily concerned with changes to the self, experienced whilst attending DBT. This emerged from three themes of ‘acceptance of self’, skills development’ and ‘change is possible’. The first theme ‘*acceptance of self*’ concerns the development of acceptance of being different from the neuro-typical world. The participants accepted behaviours and beliefs, without apparent negative judgement, that in other circumstances might be regarded as unusual.

Client 3: 'Beth brought dolly in' (P.5, L.216)

Facilitator: 'Oh Beth brought her dolly in'

Client 1: "Yeah she bought it off eBay or Facebook one of those" (P.5, L.218)

Facilitator: "And did she keep the dolly with her the whole time"

Client 3: "She had a dolly she brought" (P.5, L.220)

Facilitator: "And that was nice was it"

Client 3: "I've got mine in my box at home" (P.5, L.222)

The second theme 'skills development' consists of emergent themes such as 'development of self-control' and 'skill use'. For example:

"It actually helped me to control my anger a lot more than I used to" (Client 2, P.10, L.433)

"Look, you don't need to worry about tomorrow ok! Tomorrow, today is a new day right?" (Client 1 referring to mindfulness, P.10, L.446)

"It helps me an awful lot cause I used to, when we were in a group I used to get frustrated and the people who was leading the thing said, 'do you wanna go outside', and I said 'yeah I'll have to go outside'" (Client 2 referring to the skill of 'acting opposite' demonstrating the theme of development of taught skill use, P.14, L.654-655).

The final theme ‘change is possible’ consists of emergent themes such as the therapeutic process leads to trust’. This is illustrated by Client 2:

“I use to feel the same as you feel now, because I used to be quiet and um wouldn’t talk to people to staff how I feel. But now once it’s somebody I know I’ve told them things about how I’m feeling”. (P.15, L.691-693)

In this example Client 2 is offering support and hope to a fellow group member by providing an example of how they have changed.

Sub-ordinate theme Carers Group: Alteration to Self

The carer group sub-ordinate theme: ‘alteration to self’ emerged from the two themes ‘change to self’ and ‘insight’. It is primarily concerned with the personal impact of attendance at DBT.

The theme ‘change to self’ consists of emergent themes such as ‘development of self-control’ and ‘applying DBT to self’. For example:

“That’s, that’s probably helped me more, myself, and actually some of the relaxing things, if you think ‘ah god I’ve got something... stop and just look at something or think of something a place, a nice place that, that helps, that really does help.” (Carer 3; P.10, L.439-443).

The theme ‘insight’ consists of emergent themes such as ‘self-reflection’ and ‘DBT use’ and is

concerned with the insights carers experienced as a consequence of participating in DBT, examples include:

“I genuinely thought it was crap. Like six months it took me before I actually thought, do you know what this is actually really, really good” (Carer 1, P. 12, L.550-551) and

“whereas some people just close their mind to it and don’t wanna know. I don’t think for the customers we can afford to waste time and energy trying to get those people on board, not in this environment.” (Carer 2, P.13, L.583-586)

Sub-ordinate theme, Therapist Group: Change

The super-ordinate theme: ‘change’ emerged from the three themes ‘client change’, ‘therapist change’ and ‘service change’. This theme is concerned with changes experienced by the therapists, including changes in their perception of client ability. This is illustrated by the theme ‘client change’ which in turn emerged from the therapists ‘surprise’ at the clients’ ability to understand, learn and apply DBT skills. For example:

“I just remember coming away thinking ‘wow’, they really got it” (Therapist 5 P.9, L.414-415)

“their ability to articulate was”... (Therapist 4, P.8, L.333)

“profound” (Therapist 3, P8, L.334).

Therapists spoke of their personal experience of participating in the delivery of DBT service, as illustrated by the theme ‘therapist change’. This included experiences that had personal impact on the therapists for example

“they were listening to each other and adding to what the other had said and what that experience meant to them and it was just the most inspiring session I’ve ever had really”
(Therapist 3 P.7-8, L. 325-327)

The final theme ‘service change’ consists of emergent themes such as ‘development of a service’ and ‘effective service’ and is concerned with the therapists experience of the need to develop a flexible bespoke service model

“The kind of structure and the way that we implement it, and, and we found over a long period of time that, that you can and does work to produce results that you, the outcome is that you were talking about” (Therapist 1, P.6, L. 257-260)

“well I can’t believe this actually works” (Therapist 5, P.10, L.458).

Super-ordinate Theme: It’s Painful

This master theme includes the client sub-ordinate themes ‘emotional pain’ and ‘unsupportive environment’ and the therapist sub-ordinate theme ‘personally challenging’. This theme is concerned with the emotional consequence of attending DBT for both clients and therapist as difficult and challenging.

Sub-ordinate theme Client Group: Emotional Pain

This sub-ordinate theme concerns the shared experiences of loss and grief due to the death of loved ones and sometimes intense negative emotions such as anger or sadness experienced whilst participating in the group. It emerged from the themes of ‘shared experience’, ‘emotions are dangerous’ and ‘emotional avoidance’.

The theme of ‘shared experience’ emerged from themes such as ‘shared experience of loss’ and ‘recollection of sad memories’. An example of this is provided by client 2 who stated that one of the best things about attending DBT was hearing other group members talking about their personal bereavements and as a consequence being able to express her feeling about the loss of her grandfather. This discussion continued with both client 1 and client 3 sharing memories of close family members who had died. It is clear from this example that having the opportunity to feel an emotion such as sadness and share this experience with other group members was valued by the participants.

Client 2: “I, the best thing was when people hear about people dying” (P.4, L.154)

Facilitator: “about people dying?”

Client 2: ”yeah that was my best one”

*Facilitator: “say that again because you, used to think about your granddad
an awful lot!”*

Client 2: “yeah an awful lot it made me really upset and then you saying”

Client 3: “same with me and my granddad, I used to” (P.4, L.162)

The theme ‘emotions are dangerous’ emerged from themes such as ‘inability to tolerate emotions’ and ‘intense negative emotions are dangerous’. Participants in the client focus group provided several examples of situations in which they felt fear or anxiety about being physically attacked. While recounting these events they were anxious and even fearful, appearing to be reliving these emotional experiences albeit to a lesser degree. This required the facilitator to provide an emotional support during the session.

Facilitator: “Daisy used to storm out, oh ok” (P.6, L.270)

Client 2: “yeah. That made me feel rather sad because I was scared that she was going to shout”

Facilitator: “oh you were scared she was going to shout?”

Client 1: “we were scared of Daisy weren’t we!” (P.6, L.274)

Client 1: “yeah cause ‘client 3’ was trying to protect me and cause I used to back into the corner didn’t I. Betty just wouldn’t leave me alone. She used to hit out at me even though I hadn’t done anything, she used to attack me and still upsets [client 3] now, doesn’t it?, cause you see her around town” (P.11, L.478-482)

The theme ‘emotional avoidance’ emerged from themes such as ‘avoidance’ and ‘change is difficult’. As with the previous theme, while expressing their thoughts the clients appeared to relive emotions of sadness whilst providing their illustrations. The group responded to these situations by either attempting to avoid these difficult feelings, for example when one client referred to missing people who had previously attended the topic was quickly changed, this

response appeared unconscious. On other occasions these difficult emotions appeared to be managed by the use of taught skills:

“yeah you’ve got to do the opposite to the way you feel. So if you’re upset you’ve got to think happy and do happy so yeah” (Client 1, P.14, L.643-644).

Sub–Ordinate Theme: Unsupportive Environment

This sub-ordinate theme evolved from an integration of themes concerning experiences of lack of control over the environment; the environment not supporting change and feelings of frustration and powerlessness with the limits of available services. They included ‘frustration with services’, ‘environmental change is required’ and ‘powerlessness’.

The theme ‘frustration with services’ emerged from a number of themes such as ‘disappointment’, ‘anger at services’ and ‘criticism of service’. As illustrated in the quotes below:

Client 1: “you only get eight sessions with them and then they disappear”
(P.11, L.513-514)

Client 1: “I never had the same people all the time for one to ones”(P.12, L.535)

Client 1: “I’ve had different people and never cause it confuses me and it makes me quite agitated because once then I get used to somebody then I have to start all over again for a different person and I lash out then” (P.12, L.537-540)

The theme ‘environmental change is required’ emerged from participants’ comments about making changes in their own lives that require external forces to them to effect change. The emergent themes included ‘helplessness without support’ and ‘unable to help self’:

“I had to sort it out so my mum came up” (Client 3, P.16, L.716).

The clients also highlighted that changes to their environment made a real difference to their lives:

Facilitator: “but you said coming helped in a little bit, a way, how did it help you? Is it different now?” (P.9, L.407)

Client 2: “it’s a lot more different cause I moved, I moved now”

Facilitator: “are okay, so moving really helped did it?”

Client 2: “It, moving away from some situation it actually helped me feel a lot more comfortable in myself, that I can talk to staff now.” (P.9, L.410-411)

The theme ‘powerlessness’ emerged from themes including ‘lack of control’ and ‘problematic relationships’, in which the participants presented situations in which they had limited control. Client 1, whilst talking about the death of her grandfather, described a family member making decisions on her behalf

“she didn’t want us to go and see her, cause obviously she thinks it will all upset us and seeing my granddad” (P.5, L.192-193). Later the same client described a difficult relationship that she had with somebody she lived with:

“yeah, she used to knock on the door and then when we’d say like you know, were going out, she just walk in, she didn’t bother waiting for us to open the door, she just coming and I went to her, you can’t just come in, In someone else’s house without ourselves in the door and she went, ‘oh shut up’, to me” (P.7, L.298-302).

It is apparent from this description that client 1 had limited control over her environment.

Sub-ordinate theme Therapist Group: Personally Challenging

‘Personally challenging’ emerged from the three themes ‘emotionally challenging’, ‘cognitively challenging’ and ‘practically challenging’. It is concerned with the challenges of delivering a DBT service, the difficulty of dealing with expressed emotions from those that participate, the emotional challenge of applying the model to oneself and the emotional responses one experiences in the delivery of a DBT service such as surprise and fear.

The theme ‘emotionally challenging’ emerged from a number of themes such as ‘will DBT make a difference’. There appeared to be significant anxieties for the entire group about setting up a DBT service for example:

“we had a lot of anxiety, I think about what we were doing and trying to create meaning for ourselves” (Therapist 2, P.2, L.52-53) and later the same therapist

stated:

“there was so much hope attached to it as well you know, can we actually find a solution to this conundrum where I basically failed as a nurse” (Therapist 2, P.4, L.177-179).

An additional theme was ‘can we do it’ this theme was concerned with worries about their own abilities to deliver a service:

“we decided to introduce the concept of ending with therapy and one client just reacted so badly and dissolved into tears and everyone else started crying. We had people walking out on us...(Therapist 5, P.5, L.510-512)”.

This theme also concerned the motivation of therapists, with one therapist expressing their frustration at the struggle to deliver a service:

“I’m so tired, I’m so tired of all this.” (Therapist 3 P.12, L.513).

A further emotional challenge to therapists was illustrated by the theme ‘control the environment’ and concerns the anxiety of therapists about their ability to manage skills groups and therefore to control the environment:

“we seem to play divide and rule with our service users don’t worry, we separate them, we don’t allow them to build up relationships, we staunch their ability to

express themselves” (Therapist 2, P.8, L.352-355)

A further theme ‘Using DBT’ concerned the challenges of personal application of DBT interventions:

“I’ve been non-judgemental about ourselves and I think that’s really freeing”
(Therapist 4, P.7, L.301-302)

The theme ‘Cognitively Challenging’ emerged from a number of themes such as ‘based on DBT principles’ which were concerned with the intellectual challenge of adapting and applying the DBT model to an ID population:

“you can’t get anything done without creating a framework within the group, but there’s also the fact that is a very fluid structure and I think that a lesson we learn sort of for skills group” (Therapist 2, P.7, L.283-285)

In this example the author believes that the therapist’s reference to ‘fluid structure’ concerns the use of a dialectical approach to the therapy. This quote indicates the intellectual challenges of applying dialectical principles. A further challenge was that therapists had to work with ‘primacy of effect’ (Swales and Heard, 2009: p. 23) proposing that clients can act on emotional impulses without thought:

“it just takes into account that a lot of what happens between people isn’t intellectual is it, it’s actually about animals in the same space” (Therapist 2, P.6, L.250-252).

The theme ‘practically challenging’ emerged from a number of themes such as ‘this is challenging’ which concerned the day to day challenges of running a DBT service:

“part of my learning about DBT is you’re doing something else as well which, we’re actually keeping a bunch of disparate and quite challenging people together in the same room” (P.5-6, L.231-234). The therapist also discussed the ‘personal challenges’ of service delivery e.g.: *“I think our experience of, operating services is also one kind of very long period of, of developing as a team and developing our understanding”* (Therapist 2, P.6, L.261-263).

Super-ordinate Theme: Development

This super-ordinate theme includes the carer sub-ordinate themes of ‘personal awareness’, ‘change of practice’ and ‘insight into clients’ and the therapist sub-ordinate themes of ‘adaptability’ and ‘reflective practice’. It is concerned with improvements in knowledge, insight and the therapeutic skills of those responsible for delivering or supporting the delivery of the DBT service.

Sub-ordinate theme Carers Group: Growth

‘Growth’ emerged from the three themes ‘personal awareness’, ‘change of practice’ and ‘insight into clients’. It is concerned with the expansion of awareness experienced by the carers.

The theme 'personal awareness' comprised of the personal insights of carers participating in the DBT service:

"I genuinely thought it was crap. That six months it took me before I actually thought, do you know what this is actually really, really good. So it took me to be forced to come here, to get it" (Carer 1, P.12, L.550-553) and *"I think you've got to be certain, disposition and also you've got to have something about you to get it"* (Carer 1, P.13, L.592-593).

The theme 'change of practice' concerned changes in carer practice which included both skills development:

"I think actually when you we were talking about our residents and it was to hear other people not saying stories but how insights happened and things happened it kind of like oh yeah, yeah you know, maybe we should try some of these" (Carer 3, P.3, L.116-119)

and the mutual support provided by carers:

"the interaction between staff is good as well its almost been like a, I don't know like a mini counselling group for staff" (Carer 1, P.2, L.65-66)

The theme 'insight into clients' involved carers' understanding of client experience:

“I’d like to pick up on something X said about sharing personal things and how difficult that is, it’s difficult for us, makes you appreciate how difficult for the guys in the group as well” (Carer 2, P.4, L.155-158)

and the development of client formulations for example:

“I think that would be key for the person that we support if she could notice herself, when she needs to relax or be distracted, rather than for staff always to be prompting her” (Carer 2, P.9, L.401-403).

Sub-ordinate theme Therapist Group: Personal Development

‘Personal development’ emerged from the two themes ‘adaptability’ and ‘reflective practice’. It is concerned with the maturation of the therapists’ therapeutic skills whilst participating in a DBT service.

The theme ‘adaptability’ concerned the therapists’ ability to adapt their approach in response to the needs of the client as illustrated by a dialog between therapists:

Therapist 2: “there is a very opportunistic model, that we use with our client groups and that kind of thing. So it’s an interesting, It’s like [client] isn’t it in some aspects” (P.5, L.292-295)

Therapist 4: “I think it would be very easy to go down the path of” not doing it

properly rather than actually allowing that, so that this is certain wisdom that we couldn't have been taught.” (P.7, L.297-299)

The theme ‘reflective practice’ evolved from themes such as ‘reflection’ and ‘why does it work’. Therapists’ reflections on practice were provided:

“they were with each other every step of the way. They were listening to each other and adding to what the other had said and what that experience meant to them and it was just the most inspiring session I’ve ever had really it was so exciting that, that was possible and I think that’s where we made the shift to making it much more experiential while still having the structure” (Therapist 3, P.7-8, L.324-330)

Discussion

This research aimed to explore the subjective experiences of adults with ID attending a DBT service, their direct carers’ experience of participating in this service and their DBT therapists’ experience of delivering these services. It was anticipated that an exploration of these subjective experiences would provide insight into the affective components of DBT and, in turn, shed light on any factors that effect change (Hodgetts & Wright (2007).

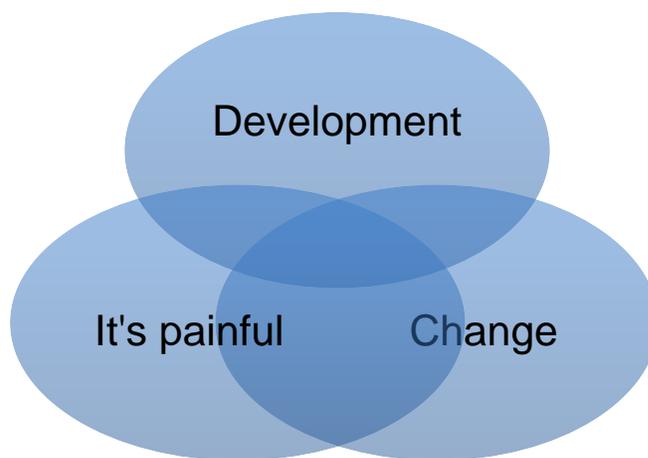
DBT has been recommended by NICE for the ID BPD population based on the assumption that DBT will be as equally effective for an ID population as it is with the neuro-typical population. As discussed in the literature review for this paper (section 2.1) current research has identified the presence of abnormal developmental processes within the ID population (Levitas & Gilson, 1988; Gaedt, 2001; Whittaker, 2001). As these differences may affect the processes that result in therapeutic change, the author believed that further exploration of this topic would be of benefit

to this field of research. Particularly so, as it was evident from the literature review undertaken that little research has focused on individuals with ID and their experience of DBT, and there has been limited examination of the personal meaning and sense-making for those participating in a DBT.

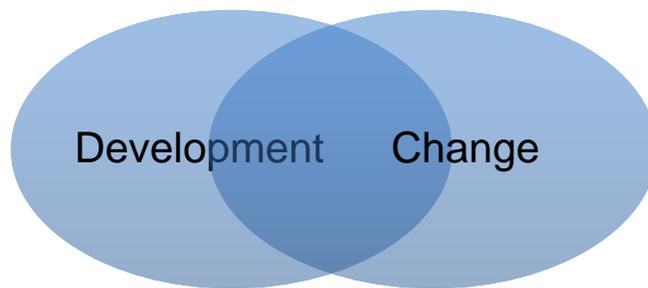
The findings of this research indicate a number of similarities in experiences across the three cohorts (clients, carers and therapists) that participated, see figure 3 below. Three super-ordinate themes were identified ‘change’, ‘development’ and ‘it’s painful’. This suggests that all those who participate in an ID DBT service will experience change and develop personally as a consequence, that this process is difficult and that this approach is effective for this population. These findings are now discussed in more depth with specific attention being paid to how they relate to theory and practice.

Figure 3. Relationship of Themes:

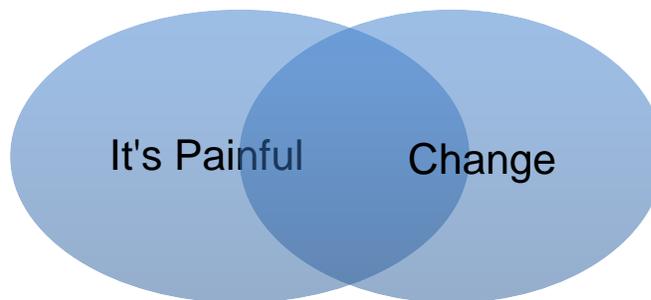
Therapist Themes



Carer Themes



Client Themes



8.1 Interpretation of Findings

The primary goal of the ID DBT service is to support the development of “a life worth living” (Linehan, 1993, p. 243) for those that attend. Theoretically this is achieved by enhancing their individual ability to regulate their emotions, maintaining and increasing motivation to change behaviour and engagement with therapy. The emphasis on supporting emotion regulation evolves from the DBT focus on the role of affect as a key causal variable leading to many of the behaviours associated with BPD. DBT highlights two particular problems with the management of affect for those individuals that struggle to regulate their emotions; they are subject to emotional vulnerability and an inability to moderate affect (Swales and Heard, 2009).

It is clear from the research results that both the clients and therapists found, on occasion, the experience of participating in a DBT service emotionally challenging as evidenced by the superordinate theme 'it's painful', (see figure 3). Clients described experiencing difficult emotional situations including at points of time being afraid of other group participants and intense shared emotional experiences such as loss and grief, as illustrated within the theme of 'shared experience'. These experiences were shared by all participants in the client group however it should be noted that although these emotional experiences were intensely felt they were not necessarily viewed as negative. The clients clearly valued the opportunity to talk about shared experiences, such as the death of a loved one, in a safe environment without being 'protected' by those that care for them as both paid and unpaid carers.

Linehan in her seminal text suggests that the most important requisite patient characteristic is "voluntary participation" (Linehan, 1993, p. 438) with this being particularly important if a positive therapeutic relationship between client and therapist is to develop. Linehan's own experience has indicated that, "One of the chief reasons for many therapy failures and early terminations is inadequate commitment by either the patient, the therapist, or both" (Linehan, 1993, p. 285). It is evident, from the client transcript (client transcript, P.1-2, L.6-55) that none of the clients initiated their participation in DBT. When asked about their best experiences in DBT none offered the example of the relationship with their therapist or group facilitator, although it is evident from the client theme 'frustrations with services' that they valued these relationships but were frustrated by inconsistency and change of therapists.

Attending DBT was emotionally challenging for these clients however they maintained their participation over a significant period of time, the question that has to be asked therefore is ‘why did they choose to do this?’. A reason for this might be that the clients valued the peer relationships developed and the opportunities to identify and share experiences. This interpretation is supported by the results of the thematic analysis carried out by Lyndsey Hall and her colleagues (2013). One of the themes identified by these researchers was ‘good things about the group’ consisting of themes including participant reporting “that it was helpful to be with others who have similar experiences” (Hall et al 2013, p. 8).

Therapists also described experiencing intense emotions while participating in a DBT service. These included fear of clients, concern about an uncontrolled environment (theme – emotionally challenging) and anxiety about their ability to deliver therapy. DBT predicts that working with clients experiencing significant emotional pain will present therapists with difficulties and therefore there is an expectation that these emotional challenges will be addressed using the DBT model within the consultation group (Swales & Heard, 2009).

Analysis of the therapist group transcript identified an unexpected emotional response; the therapists’ surprise at the clients’ abilities to understand DBT concepts to and learn and apply DBT skills, as illustrated by the subordinate theme ‘change’. The emergence of this theme could suggest that specialist ID therapists involved in this service underestimated the abilities of ID individuals and as a consequence may initially have had lower expectations of the possible therapeutic change.

The superordinate theme ‘change’ provides some evidence of the effectiveness of DBT. Clients described their use of DBT skills (theme – ‘skills development’) and therapists described observing clients learning and applying DBT skills. To some extent these findings replicate Lyndsey Hall and her colleagues’ findings in the theme ‘good things about the group’, which included client reports of the continued use of skills after their DBT group had finished (Hall et al 2013, p. 8). An expectation of DBT is that it will provide treatment to the environment that the client inhabits. There is an expectation that therapists, and/or the pre-treatment champions, will develop descriptions of factors that interfere with treatment delivery in the system and to conduct behavioural and solution analysis of “organizational therapy delivering interfering behaviours” (Swales & Heard, 2009, p. 69). It is evident from the carers’ theme ‘insight’ that the views of DBT held by carers changed as a consequence of participation, which in turn appeared to result in them championing the approach within the client support system. For example: “do you know what? This is actually really, really good” (carers transcript, P.12, L.551-552).

Another expectation within DBT is that therapists will apply the treatment to themselves in order to reduce therapy interfering behaviours that they may be engaged in. The therapist theme ‘emotionally challenging’ includes an example of such behaviour, for example: Therapist 2 states “we staunch their ability to express themselves” (P.8, L.354-355) in the context of a discussion about the therapist managing personal anxiety. DBT requires these behaviours to be addressed by the consultant team using the treatment model. It is evident from the superordinate theme ‘development’ that a consequence of participation in a DBT service for both therapists and carers is an increase in their confidence and maturation in their therapeutic skills.

It is evident from figure 3 that similar experiential relationships within and across all three participant groups were identified. Each group described experiences interpreted as representing change as a consequence of individual and group development. Greater emphasis was placed on developmental experiences by the therapists and carers than the clients. However, this is not to say that clients did not have developmental experiences but the researchers' understanding was that this was less than for the other two groups. Clients in particular but also the therapists appeared to experience this process as painful. Whilst carers also found the process challenging as highlighted in their reflections on practice this was to a lesser degree than the other two groups. It is the researchers' interpretation that all those who participated in the ID DBT service experienced change as a consequence of personal development and that this process was painful. This experience of change may explain why those who participate in DBT and those who deliver the service continue to do so even though this process is experienced as painful. It may also provide an explanation as to why both carers and therapists become such advocates for this approach, as illustrated in the carer theme of 'change of practice' and the therapist theme 'reflective practice'.

9. Clinical and Service implications

The present study highlights the need for further adaptations to the current DBT service offered in order to improve its effectiveness. Although DBT requires treatment to the environment primarily during the pre-treatment phase, it is evident from the client experience, illustrated by the theme 'unsupportive environment', that the clients who participated in this research require more intensive treatment to the environment to benefit them. The lived experience of adults with intellectual disabilities appears to be one of genuine powerlessness with regard to making change

within their environment. As a consequence this ID DBT service should, in addition to a pre-treatment champion providing support to carers in the form of the carer's group and offering one-to-one therapy, nominate and provide an environmental champion throughout the period of therapy. This individual should work alongside paid and family carers in supporting them "to modify their own behaviour to promote the sustainability of changes that clients are making" (Swales and Heard, 2009, p. 51).

With regard to the service that was examined, it is evident that at least one client participant was frustrated by the inconsistency of therapist delivering individual therapy. The development of the therapeutic relationship between client and therapist is critical in reducing the likelihood of therapy failure and or the early termination of therapy. Inadequate commitment by either the patient or the therapist threatens this relationship, (Linehan, 1993). The service therefore needs to make a greater effort to identify and manage therapists to support a consistent approach to therapy delivery.

The themes that emerged from the carers transcript 'alteration to self' and 'personal growth' could be generally characterized as positive in that carers experienced attendance as personally transformative resulting in personal development. Additionally themes such as 'personal awareness' also identified certain personal characteristics required to increase effectiveness of carer support. This feedback might helpfully be used to encourage future carer participation in the DBT service. It would also suggest that a selection process should be used to identify carers with sufficient level of motivation.

A consistent theme emerged of therapist surprise at the clients' abilities to understand, learn and apply DBT skills. In future when therapists are considering client ability, specifically regarding the impact or consequence of their intellectual disability, perhaps in one-to-one sessions or in a consultation group, this cognition needs to be held in mind. If the thought 'they won't be able to do this because they have an intellectual disability' occurs this needs to be challenged and only accepted if there is evidence to support it. The DBT model describes eight assumptions about borderline patients and therapy. The first assumption, for example, being 'patients are doing the best they can' (Linehan 1993 p106). The conclusion described above could be used as an argument for an additional assumption specific to individuals with ID for example, 'ID participants can learn, understand and apply any of the DBT skills'.

The client theme 'emotions are dangerous' and the therapist theme 'emotionally challenging' both contained examples of participants experiencing emotions such as 'fear'. The Polyvagal Theory suggests that "when a client feels safe with the therapist, the clients' physiological state can provide optimal conditions for both the client and therapist to engage in therapeutic work" (Geller & Porges, 2014, p. 179). This theory proposes that this optimal therapeutic state will occur when features of safety are detected by the nervous system (Porges, 2003, 2007, 2011). Additionally, recent research suggests that the establishment of a safe therapeutic environment facilitates the development of new neural pathways for the client and these can contribute to the repair of attachment injuries, (Allison & Rossouw, 2013; Rossouw, 2013).

The Polyvagal Theory proposes that significant features of safety are the face and voice as these are important for communicating safety to another as they are "central to human relating,

dialogue, and presence” (Geller & Greenberg, 2012, p.185). The therapist can communicate therapeutic presence by offering “warm facial connections, receptive posture, open-heart, and listening presence” (Geller & Porges, 2014, p. 179). In order for the therapist to be available and open in the presence of the client’s defence and pain, effective therapeutic work is essential; requiring the therapist to be consistently present and engaging and to be able to self-regulate (Geller & Porges, 2014). This service therefore should use the consultant group to increase the support offered to those that deliver therapy with regard to self-regulation of emotions and practical therapeutic skills development in order to support and increase the clients’ experience and sense of safety. Further practical measures need to be introduced to support clients in feeling safe with peers, for example: more opportunity for social interaction prior to the therapy group commencing.

9.1 Limitations of the Research

In an effort to undertake good quality qualitative research, Lucy Yardley’s criteria were considered and the current research study met the four criteria: sensitive to context; commitment and rigour; transparency and coherence; and impact and importance (Yardley, 2008). The research was carried out within an established ID DBT service. An examination of the subjective experiences of all those participating in the service was undertaken with an aim of gaining insight into the experience of those receiving and delivering the service. It was hoped that this insight might provide an opportunity to improve the quality of the service provision. The researcher believes that this research is sensitive to its context, transparent in its objectives and processes and that the impact is important in terms of service development, as well as the wider context of research. Despite this effort the researcher acknowledges several identified limitations.

Firstly, IPA analysis involves interpretation of the data and the researcher drawing on their own experiences in the interpretation. The researcher undertaking this project has had a long history of involvement with the participants and the service, resulting in a challenge to the process of bracketing. However, this potential weakness could be considered a strength as the researcher's familiarity and experience with the research participants arguably enabled a greater depth of analysis. This may also have reduced levels of participant anxiety experienced resulting in a greater degree of trust than might otherwise be expected and in turn may have resulted in a greater participant willingness to share thoughts.

Secondly, many of the carer participants are likely to be subject to selection bias. Those that chose to participate may have been particularly committed to the DBT carer group and therefore likely to be subject to a form of self-selection bias. In addition, due to the limited resource of the researcher it was not possible to apply Palmer's protocol for using IPA fully with the focus group data however the principles of the process were adhered to. There were also a number challenges with regard to recruiting clients who met the diagnostic criteria for borderline personality disorder. The inability to pilot the focus group questions and to have a control group are further weaknesses. As previously discussed, clients made little reference to their experiences with their one-to-one therapist and such potential gaps may have been identified if it had been possible to pilot the focus group questions.

Finally, the choice of IPA methodology clearly limits the ability to generalise the findings. Smith argues for the notion of 'theoretical generalizability' in his seminal text, suggesting that the

reader of IPA research can make judgements about the evidence presented in relation to their existing experiential and professional knowledge and draw their own conclusions (Smith, 2009).

10. Future research

The American Psychological Association's (APA's) presidential task force on the evidence base practice "highlighted the importance of clinical expertise and patient characteristics as essential factors in evidence based practice" (Laska, Gurman & Wampold, 2013, p.468).

As highlighted within this research it is common practice within the intellectual disability population for those that support this client group to refer and encourage them to access therapeutic support. Research examining the impact of this client characteristic is warranted.

This research found that experienced intellectual disability therapists were surprised at their client's abilities to understand, learn and apply behavioural or acceptance skills. Gallagher proposed that there is "a strong tendency to assume a lack of skill or understanding, when a lack of motivation, lack of experience, or emotional factors may be the cause of difficulties' within therapy" (Gallagher, 2003, p. 207). At present there is very little literature examining the impact of therapist beliefs and assumptions on therapy. Further research examining the impact of these characteristics is also warranted.

This research has added some anecdotal evidence to the existing small body of evidence supporting the use of DBT with adults with intellectual disabilities and further research is required. Research based evidence is critical to the establishment of new services or interventions and necessary to support existing services (Bhaumik, Gangadharan, Hiremath,

Swamidh and Russell, 2011).

11. Conclusion

This is the first research paper to examine the experiences of those participating in an ID DBT service using IPA. Three superordinate themes were identified, 'change', 'development' and 'it's painful'. Findings suggest that both clients and therapists found, on occasion, the experience emotionally challenging. As a consequence of personal development change was experienced and this process was painful. It adds to the evidence of the effectiveness of DBT and suggests that a consequence of participation in a DBT service, for both therapists and carers, is an increase in confidence and maturation in therapeutic skills. It identified several issues to be considered when implementing or delivering this service. The clinical implications described are supportive of the use of DBT with this client population and provide a rationale for the further development of such services.

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Section Three: Critical Appraisal of the Research

1. Introduction

The following critical appraisal is written based on the research diary that I have kept over the last five years while engaged in the doctoral program. It consists of a detailed critique of my research and will describe my learning, the strengths and weaknesses of the research, how it might have been improved, the outcome of the project and my thinking regarding future research opportunities.

2. Choice of Project

My interest in working therapeutically with individuals who receive the diagnosis of Borderline Personality Disorder (BPD) developed early in my career as a psychologist. I had been working with a young man for approximately two years using a behavioural approach with arguably some success. However, as a result of his inability to manage his emotions, his behaviour was determined to be unmanageable by his service provider and his placement broke down and he was moved to a semi-secure unit in a remote part of the country. From my perspective this young man had a great deal of unrealised potential and I was very saddened and frustrated by this outcome. Following reflection on our work together I concluded that I had insufficient knowledge to work with this presentation and, as a consequence, I sought out training in Dialectical Behaviour Therapy (DBT). DBT at this time being one of the few therapeutic models with an evidence base to support its effectiveness with this client population, as it was specifically designed for therapeutic work with individuals with a diagnosis of Borderline Personality Disorder. To this end, in 2005 I completed an intensive training course in DBT and in 2011 a post graduate certificate in DBT.

In 2008 I was tasked with developing an adapted DBT service for adults with intellectual disabilities (ID) in rural England (Baillie, Slater, Millington, Webb, Keating & Akroyd, 2010). This service has been running since October 2009. When the service was established little literature existed describing how one might adapt DBT for an ID population, a concern for the team was how to evaluate its effectiveness. In response to this concern, a colleague and I developed a carer completed questionnaire: the 'DBT Carer Feedback Questionnaire' (see appendix F). In addition to 16 questions that examine perceived change in the four skills that are taught in DBT, there are two additional questions designed to obtain qualitative data about the use of these skills. Using this questionnaire some qualitative data has been collected however this data primarily focuses on the use of taught skills.

Therefore, there were a number of pragmatic reasons for the choice of my research project including the fact that I had easy access to an ID DBT service. I would be supported by my employer and management team because the outcome of my research would contribute to our ongoing service evaluation programme (Slater and Baillie 2008 & 2011; Baillie & Slater 2014) and potentially lead to service improvements. Our evaluations to date have provided some evidence of effectiveness (Baillie & Slater, 2014). DBT is considered a relatively expensive service to provide by our commissioners and the absence of any significant body of literature supporting its effectiveness is a challenge to arguing for its continuation. I believed that research examining the subjective experience of adults with ID receiving a DBT service would be of great interest to our commissioners, alongside the service evaluation I have carried out as part of the doctoral programme.

I have described a number of practical and pragmatic reasons to choose this research topic but they were secondary to my primary curiosity ‘why do clients with ID attend and participate in our DBT service?’ DBT requires commitment, hard work, is intellectually challenging, time consuming and can have a significant duration. I have observed individuals over several years attend initially because other people e.g. carers, family or professionals thought they should. They appear to continue to attend because they value the social interaction and the relationships they develop. They are rarely self-motivated or have obvious desire to change their own behaviour, generally offering reasons for their attendance such as ‘*Um I got referred by my social worker, she, she thought it could help me do, learn, how to control anger, so.*’ (page 1 - client transcript) and yet I have observed behavioural change and development of emotion regulation skills in these clients and this is supported by our quantitative evaluations, that is; our data has found reductions in the behaviours of concern and increased skill use (Baillie & Slater, 2014).

As a consequence I became very curious about the essential ingredients of this change. The idea of that there may be common factors that are essential for therapeutic change is controversial and is the topic of on-going topic debate within psychotherapy research (Imel & Wampold, 2008). This debate concerns the question of whether the essential ingredients of therapeutic change are non-specific ‘common’ factors or specific factors (techniques) (Tschacher & Pfammatter, 2016). I was particularly interested in exploring the possibility of ‘common factors’ that may result in therapeutic change within the intellectual disability population.

A number of researchers have developed common factor models, one of latest being Michael Lambert who proposes “three classes of common factors: supportive factors, learning factors, and action factors”, it is his contention that “supportive functions precede changes in beliefs and attitudes, which precede the therapist’s attempts to encourage patient action” (Lambert 2013, p.173). Therefore, I wanted to take the opportunity to explore the possibility of common factors of change that underpin my clinical experience by examining the personal meaning of attendance for our clients and how they make sense of the experience of participating in DBT. I hoped that by starting the process of identifying such factors and making adjustments I could develop a service tailored specifically for adults with intellectual disability. The hope is that this would result in a more supportive service, increased retention rates, speed up the process of skills acquisition and increased motivation to engage in change.

3. Choice of Methodology and Design

I chose IPA primarily because it would allow me to explore the lived experience of a client or carer attending our DBT service and the therapist’s experience of delivering it. I was especially interested in how these individuals related to this experience that is how they made sense of it.

In addition there were a number of pragmatic reasons for choosing this approach; firstly IPA is well suited to research questions that are not particularly theory-driven. Although I had an interest in theories (referred to above) put forward to explain therapeutic change I did not have a solid hypothesis as to why it may occur in the ID population. IPA also allowed for a small sample size and the lack of existing standardised measures.

I considered a number of alternative qualitative approaches such as narrative psychology but as I was interested in the subjective experiences of the participants rather than the story structures they used to describe their experience of attending DBT. Particularly as it is my experience that ID individuals often pick up the dominant narrative within their environment e.g. a number of clients have told me they attend DBT because they have ‘anger problems’ and I believe is a consequence of hearing staff offer this explanation for their attendance and therefore did not feel a narrative approach was appropriate. I also did not want to primarily focus on an explanatory account that focuses on the factors that might influence attendance/participation of a DBT service, for example client a saying ‘I go to DBT because I cut my self’. I chose not to use grounded theory.

The most significant reason for my choice of IPA however, was the requirement within IPA that the analyst “uses themselves and their own thoughts, feelings and experiences as a touchstone” when making sense of the data (Smith, Flowers & Larkin, 2009, p.90). I had known and interacted with all the likely participants over a significant period of time and was sure that I would be unable to avoid my participation when interpreting the data and also wanted to express my lived experience.

I realised that the decision to use focus group methodology would result in a dialectical tension within the project. When IPA was developed it was significantly influenced by ‘idiography’; committed “to understanding how a particular experiential phenomena (an event, process or relationship) has been understood from the perspective of particular people, in a particular context” (Smith et al, 2009, p.29). This means IPA is suited to single case studies rather than

interactional complexity of a focus group. As this interactional complexity makes it more difficult to develop personal and ideographic accounts resulting in narratives and reflections that are fairly complex in their social and contextual relationships (Smith, 2009). Based on my clinical experience with ID individuals I was certain that I would obtain a greater depth of response in a group context rather than a one-to-one basis and therefore felt this compromise was necessary for this project.

4. Recruitment

Recruitment of participants proved to be a greater challenge than I initially predicted; as the clinical lead for an established ID DBT service I believed recruitment would be a fairly straightforward proposition particularly as the selection of IPA and focus group methodology meant relatively few participants were required. In reality obtaining sufficient numbers of clients and carers proved a challenge; in fact, it was only possible to obtain four carers for the carers' focus group and three clients for the client group.

There were a number of reasons for these difficulties. Firstly; the doctoral program can take between two and five years and at the point my research proposal and methodology were approved by the university there were potentially 6 to 8 participants for each of the three focus groups that met the criteria for participation in the research project. However, obtaining ethical approval, ensuring consent was properly obtained and other pragmatic challenges meant that the focus groups did not take place for some two years after the receipt of approval for my research proposal. During this period a number of potential client candidates had either moved out of area or were placed out of county, one was not available on the day and one individual agreed to

attend but did not turn up. Although there were several new participants in the DBT service they did not meet the eligibility criteria for participation in the research project.

There were also a number of difficulties in obtaining carer participants, some had left their posts and moved onto other work, others had left the area and several were unavailable on the day due to work commitments. Those that did manage to participate were carers that had been particularly committed to the DBT carer group and therefore likely subject to a form of self-selection bias.

The only group that it was relatively simple to obtain participants for was the therapists group; seven out of a potential nine therapists participated. This was the case even though I made a genuine effort to ensure any of the therapists would feel comfortable to opt out. I reminded them of the DBT principle of ‘observing limits’; we try not to operate beyond one’s personal limits. (Linehan 1993).

Arguably, the most significant consequence of these difficulties was that it was not possible to ensure that all the client participants had a formal diagnosis of Borderline Personality Disorder. Only one of the three did have this diagnosis, of the remaining two one was described by her psychiatrist as having ‘a borderline personality disorder type presentation’ and the final participant was diagnosed as having ‘emotion regulation difficulties’. This challenge was discussed with my supervisor and it was agreed that these participants were typical of ID clients receiving DBT as can be seen in the literature review carried out for this research.

5. Focus Group Process

The focus group process was both interesting and challenging; much of the data acquired I found surprising and interesting, however, there were a number of difficulties with the design of the focus group questions and the facilitation of the groups themselves.

The questions for the three focus groups involved using the 'questioning route' approach which is a 'sequence of questions in complete, conversational sentences' (Krueger & Casey, 2009, p.38). All three sets of questions included an introductory question, key questions and an ending question. The introductory question was intended to allow the participants to account a fairly descriptive episode or experience and was relatively successful in making the participants feel comfortable to talk (Smith et al, 2009). The key questions were 'open', 'narrative', 'circular' and 'comparative' in design and, again, arguably successful in eliciting in-depth responses. The ending question was designed to enable participants to reflect back on their previous comments (Krueger & Casey, 2009) and was relatively successful for the carer and therapist focus groups but probably less so for the client focus group. The clients appeared to struggle to answer this question by linking it back to their previous comments, which was likely due to their cognitive impairments.

The lack of a pilot study and the opportunity this would have afforded to pilot the questions was significant; I believe I drafted insufficient questions, particularly for the client group, and as a result had to prompt responses on multiple occasions. In addition there were periods during the group where I allowed the conversation to drift because I did not have a planned question to ask.

The lack of questions and possibly my confidence to develop questions on an ad hoc basis during the process resulted in the sessions being shorter than I had originally planned.

6. Transcribing

The methodology chosen (focus groups) resulted in a relatively small amount of material to be transcribed; approximately two and a half hours of audiotape. This allowed me to spend time developing a relatively detailed transcript. All participants' roles were identified, including the group facilitator, and each participant was given an identifying code although this did not mean any one contribution was more relevant than any other.

I decided to represent audible speech in a standardised form using the grammar and spelling conventions of standard UK written English e.g. punctuation and capital letters as I believed it would be much easier to read and understand. This did risk the loss of linguistic variety that might be particular to the subcultural identity of this client group. On balance I felt that this would be worthwhile exchange as representing linguistic variety using literal spelling would be difficult to read and understand.

I chose to include false starts, repetitions, interruptions, overlaps, laughs and encouraging noises (such as “mm”) even though these may have cluttered the text. Some interpretations were made during transcription for example laughter was recorded as ‘laughter (one second)’ rather than ‘he he he’. This level of detail was included as it contained important information that was used during the analysis. Although my familiarity with the participants aided understanding and deciphering of difficult to understand speech, this was not always possible and in these cases it was recorded as undecipherable.

7. Analysis

The process of transcribing the collected data, although time consuming and hard work was an important component of the data analysis, as it offered the opportunity for me to become very familiar with the data (Smith, 2009). This familiarity was required because of the decision to collect the data using focus group methodology and analyse it using IPA. The decision resulted in a particular analytical challenge as IPA was originally designed to analyse data derived from individual clinical interviews (Smith, 1996).

The analysis of the focus group data collected in this study needed to acknowledge the presence of “multiple voices” and the additional complexity of both shared and individual contexts plus of the discussion itself, in practice this meant I needed to analyse the data twice. I identified a protocol developed by Palmer, Larkin, De Visser and Fadden (2010) which describes an eight step analytical process for working with focus group data using IPA. When I examined this process in detail it became clear to me then I had insufficient data and personal capacity to carry out the analytic process described by Palmer and her colleagues. I decided that I would use the principles of this model within an adapted version of Smith et al’s (2009) six-step model. I analysed the data using Smith’s model until I reached step six (looking for patterns across cases) at this point I re-examined the data considering the questions identified by the eight-step model developed by Palmer et al (2010).

8. Bracketing

Throughout the research process I attempted to put aside my own understanding and beliefs about participating in and/or receiving a DBT service with varying degrees of success. But, as

outlined by Smith in his seminal text, bracketing is “something which can only be partially achieved” (Smith, 2009, p25). As Smith recommends, I acknowledged my preconceptions during the analysis process, when engaging with the participants and particularly when I was attempting to interpret the data. In order to reduce the impact of these preconceptions on the analysis process I worked hard to focus on the task in hand, whether that be facilitating the focus groups or analysing the data, more than the process of bracketing prior concerns. I attempted to carry out these processes in a mindful manner, for example; attending closely to the participant’s story and attempting to facilitate the uncovering of his/her experience.

8 Critiques And Limitations Of Research

This research could rightly be subject to a number of critiques, which I will now explore in some detail.

As mentioned earlier, recruitment proved a challenge. In the end a total 14 individuals took part in this research. Although initially I would have preferred a greater number of data points, 4-10 participants are recommended for professional doctorates when using IPA (Hofferon & Gil-Rodriguez, 2011). Smith et al (2009) suggest that sample size is contextual and should be considered on a study by study basis, that as IPA emphasises a commitment to idiography it is better to examine fewer participants in greater depth than have too many examined to a shallow depth (Reid, Flowers & Larkin, 2005). Therefore, I believe sufficient data points were examined to ensure a valid piece of research.

Consideration was given to using a control groups but this idea was dismissed for a number of practical reasons. Firstly, participants would have been very difficult to recruit. A few individuals receive a service from members of therapist focus group for emotion regulation

difficulties as well as support from their carers but the number of possible participants is very small. Secondly, even if it had been possible to identify sufficient numbers of individuals to form a homogeneous sample group large enough to allow for control groups, the resulting project would have been outside the scope of my capacity.

A reasonable question might concern the small number of super-ordinate themes developed from the client focus group data. I believe this is a consequence of the effective depth of analysis. My alternative was to present a larger number of super-ordinate themes with insufficient data extracts to support each theme. Hofferon and Gil-Rodriguez (2011) suggest that a more thorough and synthesised analysis tends to be represented by a smaller number of themes. However, I have to acknowledge that if I had developed sufficient additional questions for the client focus group this may have resulted in additional material to analyse.

A clear limitation of this research, as a consequence of choosing to use IPA, is the inability to generalise the findings. I hope however, that as Smith et al (2009) argue they have “theoretical generalizability”; it may be possible for the reader to “assess the evidence in relation to their existing professional and experiential knowledge” (2009, p.4). The DBT input being examined within this research was an adapted version of DBT and was implemented concurrently with pharmacological therapy in the client groups’ case.

This research has a number of additional weaknesses which have been explored in some detail already in this paper. These include the concern that IPA is not ideally suited to focus group methodology and that many of the participants would likely be subject to selection bias,

particularly those who participated in the carer focus group. Others include my inability to apply Palmer's protocol for using IPA with the focus group data in an adherent manner and the difficulty of recruiting clients who met the diagnostic criteria for borderline personality disorder. The inability to pilot the focus group questions and have a control group are further weaknesses. My own long history of interaction with all those involved in this research resulted in a challenge to the bracketing process.

It should be noted within this critique that some of these weaknesses described also could be considered strengths, for example; my familiarity and experience with the research participants allowed a greater depth of analysis in my view. I believe it also reduced their anxiety resulting in a greater degree of trust than might otherwise be expected, increasing their willingness to share their thoughts.

I believe an examination of this research using Lucy Yardley's framework for validity in qualitative research (Yardley, 2008) would find it worthwhile when considering the four broad principles: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. I believe the specific topic of this research addresses a particular need that is increasing the effectiveness of DBT with my local an ID population and therefore demonstrates sensitivity to the context and impact and importance. My personal dedication to this local service and to this research project demonstrate commitment and the method section of the research paper demonstrates transparency.

9 Organisational Issues or Obstacles Confronted During The Study

During the process of completing this research a number of organisational changes have occurred that have had an impact on the project. My role changed and demands on my time increased, which in turn made the task of completing this research more challenging. I have been TUPE transferred twice and this resulted in a requirement for me to make the case to the new head of research for this project to continue. We have been subject to a CQC inspection in which this research was highlighted positively as an example of on-going service evaluation.

10 Future Research Opportunities

Further research examining whether non-specific ‘common’ factors, or specific factors (techniques), are essential ingredients of therapeutic change within the ID population receiving a DBT service. Specifically, further investigation into the common factors that may result in therapeutic change, such as Lambert’s hypothesised three classes of common factors: supportive factors, learning factors, and action factors would be of value. As it would be relatively easy to make changes to DBT service structure based on research findings.

11 Reflections on Personal And Professional Development

The task of this doctoral program has been a constant companion for five years now and I regularly ask myself why and I choose to take this on. One might legitimately argue that as a senior psychologist working within the NHS for some 16 years it was unnecessary, however I personally have found this is a very valuable and rewarding experience.

I value the insight I have gained into the demands and expectations placed on trainee psychologists that I supervise, the knowledge I have developed with regard to qualitative

methodology, the further development of my general research skills, the intellectual stimulation and occasional moments of excitement when I have experienced some epiphany.

In terms of my professional development I expect to publish at least three papers as a consequence of this work, which will add to my existing body of publications, thus maintaining my reputation within our trust as an evidenced based practitioner who facilitates and carries out research. In addition a very practical benefit for my private practice will be the use of the title of 'doctor'.

This research has resulted in a number of practical changes to the DBT service; these primarily focus on increasing the sense of safety and security the participants experience when they attend. Practical attempts to increase these feelings have included increasing the time and opportunity for social interaction for the clients. This process has facilitated a deeper understanding of DBT and its application to an ID client population. I have been intellectually stimulated and re-energised by this process and look forward to sharing the findings with my colleagues and the subsequently discussions that follow.

12 Publication

To date, the critical literature review has been submitted and accepted for publication within the Journal of Clinical Psychology and People with Learning Disabilities (subject to few revisions). A colleague and I are making changes requested by the editor and I hope it will published in an early 2017 edition. In addition, I have started to explore options for both the research and service evaluation papers.

13 Conclusion

In conclusion, this project has not been without challenge; as a full-time employee within the NHS with my own small private practice, the additional demands of this doctoral program have been difficult to manage and on occasion have required sacrifice from family and myself. It has resulted in changes to our DBT service (hopefully increasing its effectiveness), examined the subjective experience of our clients, which is rare (and I would argue, valuable), and therefore has been a worthwhile, interesting and stimulating challenge.

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Section Four: Service Evaluation

An evaluation of an Adult Community Learning

Disability Dialectical Behaviour

Therapy service.

1 Executive Summary

This evaluation found little evidence that an adapted version of Dialectical Behaviour Therapy (DBT) delivered by a community health team had any effect on the use of emotion regulation skills taught within skills groups, to individuals with intellectual disability (ID). A literature review undertaken of services where DBT was used with an ID population identified a small number of papers. The authors of those papers had all argued for DBT being an effective intervention for this population, however, a closer inspection failed to find any hard evidence to support these claims. This paper describes the evaluation of data extracted from a carer completed outcome measure questionnaire developed to examine perceived change in the use of four skills taught at a DBT skills group. It employed a single group pre-test and post-test design. The independent variable was DBT adapted for individuals with an ID, and the dependent variable being the carers' perception of an increased use of the emotion regulation skills. Eleven sets of data were used as pre and post measures, each dataset consisted of 18 questions that were completed at two points in time. This data was analysed using a signed rank test in SPSS and identified a single significant result, a visual examination of this finding suggested this was likely to be a statistical anomaly. The questionnaire also contained a single question designed to obtain qualitative data which provided some anecdotal evidence in support. This evaluation offered no hard evidence for the effectiveness of this approach but offers some support in the form of anecdotal evidence and therefore mirrors the findings from the existing literature.

In the researcher's view, the primary reason for this outcome is a lack of research validity across the evaluation process. In response to this critique, a comprehensive set of recommendations

have been made. These include changes to the data collection process, the nature and amount of demographic information collected and to the management of group facilitation. A search for standardised ID measures will be undertaken and other DBT services will be contacted to explore the possibility undertaking large scale evaluations. The author will also consider the use of alternative methods of evaluation, for example; single case methodology.

The evaluation has highlighted the genuine challenges of under-taking such a task effectively in a community health setting, more time and energy must be committed in future in order to increase its validity.

2 Introduction

2.1 Study Rationale

A cross county Dialectical Behaviour Therapy (DBT) service for adults with an intellectual disability commenced in 2008, with a full service established in October 2009. The steps taken to set up this service are described by Baillie et al (2010). The service was established in response to identified clinical need; a significant number of individuals with an intellectual disability and a diagnosis of BPD had been placed in large residential homes out of county, with a further group presenting similarly for placement consideration. The main reason for these placements was the lack of provision for individuals presenting with challenging behaviours apparently due to their inability to manage emotions. At this time the Department of Health Good Practice Guidance (2007) noted that many services were using outdated delivery models and still had ineffective integration arrangements which led to people with intellectual disabilities getting stuck in the system and/or being placed in inappropriate services. It was determined that a local solution was needed to meet the needs of these individuals as described by Slater & Baillie (2008; 2010).

The selection of the therapeutic approach of DBT for the individuals concerned came about for a number of reasons. Firstly, DBT is a multi-model treatment programme designed primarily to apply to individuals with a diagnosis of Borderline Personality Disorder (BPD). As this approach considers BPD to be a set of deeply entrenched problems arising from difficulties regulating their emotions, the service felt intuitively that there would be a fit between clinical need and therapeutic approach.

Secondly, Linehan (1993) places great emphasis on the impact of invalidating environments in the development of BPD also a very common feature of the life experience of people with intellectual disability; sexual abuse for example is very prevalent in this group (Miltenberger, 1997; cited in Lew et al., 2006). The latter authors also provide some examples of how the wishes, dignity and self-worth of adults with intellectual disabilities are frequently invalidated; often experiencing rejection and being ignored. The long term consequence of experiencing invalidating environments inevitably results in skills deficits in interpersonal skills and emotion regulation; therefore a therapeutic approach like DBT which emphasises the importance of skills training is well suited to an intellectual disability population.

At the time the service was established, very little literature existed on the effectiveness of DBT with an ID population however there was evidence for its effectiveness when treating BPD (Linehan, Armstrong, Suarez, Allman & Heard, 1991; Linehan, Tutek, Heard, & Armstrong, 1994; Linehan & Heard et al, 2006b). In order to support service development an ongoing process of literature review was set up resulting in the identification of the following articles (Baillie et al, 2011 & 2014; Brown et al, 2013; Charlton & Dykstra 2011; Hall et al, 2013; Lew et al, 2006; Morrissey et al, 2011; McNair et al 2015; Sakdalan et al, 2010 & Verhoven et al, 2011). A review of the samples contained within this literature found no overall consistency in reporting of characteristics of participants. The articles describe small, unmatched population samples and only one paper reported the use of a control group (Morrissey and Ingamells 2011). Little general demographic information was reported, reducing the possibility of replicating the studies and this makes assessment of potential generalisability of the findings difficult. No studies reported using a randomised control trial (RCT) design, significantly increasing the

difficulty in making comparisons between studies (Klien & Miller, 2011). One paper provided details of staff training in the application of DBT (Brown et al, 2013) and one paper made mention of confounding variables such as medication, Lew et al (2006). All the articles referred to the simplification of the educational materials used, however, no details were provided regarding how these materials were developed, piloted or evaluated. This variation in sample information was a common feature across all the papers examined and is unsurprising as the samples were drawn from individual clinical settings with small populations.

A variety of methods were used to examine effectiveness within these papers including client and carer completed questionnaires, repertory grid techniques, thematic analysis, the presentation of descriptive data and the inclusion of anecdotal evidence. There was no ID specific standardised evaluation tool or consistency in the use of any of these evaluation tools. Baillie et al (2014) suggests that identifying appropriate assessment measures for this population presents as a particular challenge. The common practice appeared to be the examination of generic tools adapted for an ID population or for services to have developed their own tools. A number of articles offered anecdotal evidence in support of effectiveness (Baillie and Slater, 2014; Verhoeven, 2010). Examples of this evidence included statements such as: “the most dramatic improvements I have seen are in cases of serious self-injurious behaviour reduced from several times a month to none over a period of months” (Verhoeven, 2010, p.334).

All the articles reviewed examined effectiveness and argued that DBT is an effective intervention for this population. However, a detailed examination of the evidence failed to identify any hard evidence. The authors’ arguments were relatively circumspect and couched in

language that acknowledged the lack of hard evidence. For example Morrissey and Ingamells concluded that: “adapted DBT [is a] feasible and promising therapeutic approach” (2011, p.15). The question as to whether DBT is an effective treatment for individuals with an intellectual disability is not readily answered by the literature to date. In these circumstances, an evaluation of the effectiveness of this approach has been a service goal of the service.

2.2 Clinical Context

Between March 2012 and September 2015 the ID DBT service delivered weekly one-to-one therapy and an adapted client skills group training (covering the four core concepts of mindfulness, distress tolerance, emotion regulation and interpersonal effectiveness) with each module lasting between 10-12 weeks. Adaptions included simplification of materials, extended treatment time and multiple repetitions of treatment. A more detailed description of service adaptations can be found in Baillie and Slater (2013). A separate weekly carers group covered the same course material as the client skills group. Additionally, therapists and skills trainers met fortnightly for a consultation meeting (peer supervision). Telephone consultation was available to clients. There were two periods of six months when the skills groups were interrupted due to building moves and staffing issues. During the period under review the DBT team consisted of a mix of chartered psychologists, an assistant psychologist, trainee clinical and counselling psychologists and intellectual disability nurses.

3 Aim of the Study

This study aims to add to the existing body of research examining the effectiveness of DBT with adults with intellectual disabilities.

Research question: Following attendance of a minimum of two of the following DBT skills group modules (mindfulness, distress tolerance, emotion regulation and interpersonal effectiveness), what change in the use of the emotion regulation skills will occur?

Hypotheses

It is predicted that there will be an increased frequency of use of all four DBT taught skills over time.

4 Method

4.1 Design

This evaluation employed a single group pre-test and post-test design to examine the impact of attending a DBT skills group on adults with intellectual disability's use of skills. The independent variable for this study was the delivery of an adapted DBT skills group. The dependent variable was carers' perception of the frequency of use of the DBT core skills by the clients, as measured by a specifically designed questionnaire.

4.2 Measure

To support a service evaluation process, two years after its establishment, the DBT service reviewed the availability of psychometric tools to evaluate outcomes. At this point in time the search met with limited success, only identifying the EQ-5D and Health of the Nation Outcome Scale-Learning Disability version (HoNOS-LD), (Roy et al., 2002). In response to this shortfall the service developed its own carer completed questionnaire the ‘DBT Carer Feedback Questionnaire –DBT CFQ’ these are described below.

The EQ-5D is a standardised instrument for use as a measure of health outcomes developed by the EuroQol Group, it provides a single index value for health status and a simple descriptive profile. The measure was administered once during a skills group in November 2011. The groups’ participants complained that it was too difficult, appearing anxious during the process of administration. The data collected was reviewed and identified that the participants had only used the scale extremes. The service decided against further use of this measure based on these findings.

The HoNOS-LD is a scale to measure the health and social functioning of people with intellectual disabilities with mental illness. This measure was administered between January 2011 and January 2012 on a quarterly basis. This outcome measure is designed to be used pre and post intervention but can be used to measure any change. The ID DBT service decided to administer this on a quarterly basis as a matter of convenience. Initial data analysis using the HoNOS-LD software carried out in January 2012 failed to identify any statistically significant

change. The service reviewed its use and determined that it lacked sufficient sensitivity and therefore its use was discontinued.

The 'DBT Carer Feedback Questionnaire' (DBT CFQ) (appendix F) was designed by the author and a colleague. It consists of 16 questions that examine perceived change in the four skills taught at DBT skills group (mindfulness, emotion regulation, distress tolerance and interpersonal relationships) with 6 point Likert scale responses. The questionnaire measures frequency of use of the skills taught in DBT, with responses falling into the categories of 'never', 'up to 20% of the time' etc. It is divided into four subscales each made up of four questions with each subscale examining one of the taught skills. All of the 16 items were derived from clinical knowledge and were randomly allocated. Additionally a further question is asked to obtain qualitative data about the use of the taught skills. There are two final closed questions which are intended to examine perceived change in self-harm rates over the preceding 4 weeks.

Following an initial pilot, the questionnaire was reviewed in January 2012 and received several criticisms. The most significant of these was that the original scale was difficult to understand. As a result, the questionnaire was revised and piloted again in March 2012, the carers' response on the whole was positive; describing the new questionnaire as 'easier to understand'. The service decided to use the DBT CFQ as its main evaluation tool from this point forward.

4.3 Participants

The carers that completed the DBT CFQ are paid carers, rather than family carers, for individuals attending the DBT service. The clients they supported were made up of individuals

with 'Mild' to 'Moderate' intellectual disabilities. These individuals have severe emotion regulation difficulties and had engaged in risky behaviours such as suicidal or para-suicidal behaviours, self-harm, excessive consumption of alcohol, risky sexual behavior and or verbal or physical aggression. Table 1 consists of a breakdown of presenting characteristics of those clients who attended DBT skills group between October 2009 and December 2013 and who are typical of the clients that attended the service (Baillie & Slater, 2014).

Table 5. Client Characteristics.

Client Presentation	Nos	%
No. of males	11	58%
Criteria for BPD diagnosis met	3	16%
Severe emotion regulation problems	19	100%
Suicidal or para-suicidal behaviour	9	47%
Risk to self	5	26%
Verbal or physical aggression	13	68%
Autism spectrum condition	4	21%

Eleven completed DBT CFQ sets of data were completed by carers and examined within this service evaluation. The clients consisted of seven women and four men aged between 20 to 53 years old and only one client met the diagnosis criteria for BPD.

4.4 Ethical Approval

Approval was sought from the senior research and development manager within the NHS trust in which the service evaluation took place. Full approval for the research project, including the service evaluation, was given on 15th November 2013.

4.5 Procedure

The DBT CFQ were distributed and completed once at an early point within each 10-12 week skills module (week 1 or 2) and then again towards the end of the module, between March 2012 and September 2015. They were completed by the carer supporting the client to attend the skills group on that given day. Every effort was made to ensure that all participant carers completed the questionnaire at the same point in time within each module however on occasion this was not possible. A review of the time points of the data collected indicated significant variation.

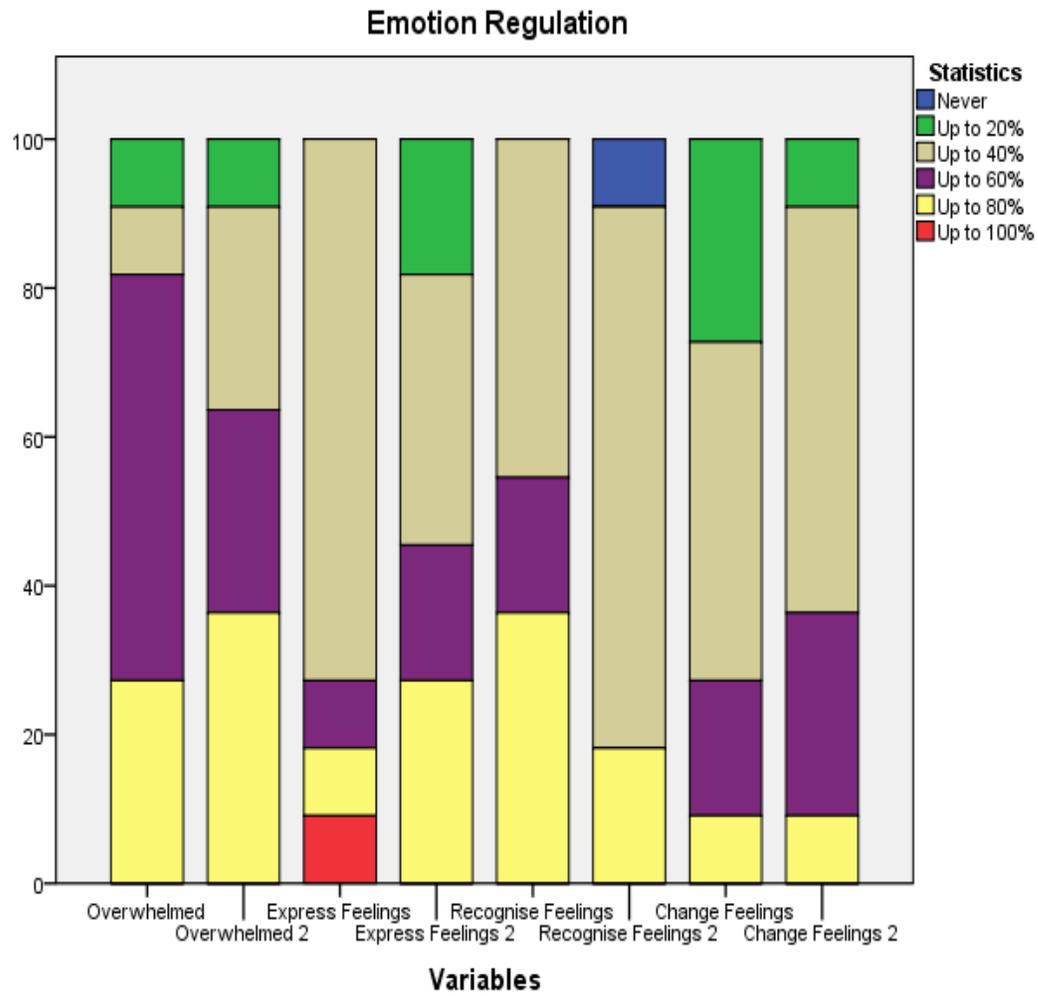
Raw data was extracted for each of the 16 questions that examined perceived change in the four taught skills (mindfulness, distress tolerance, emotion regulation and interpersonal effectiveness) within the client group at two points in time. The data was then clustered into four subscales, each cluster contained the data from four questions pertaining to one of the taught skills. The data was also extracted for the two final closed questions which examined perceived change in self-harm. This resulted in a total of 18 questions for each data set. A review of the data identified 11 potential sets of data, with single assessments being discarded, which were then analysed using SPSS. Finally, a visual inspection of the responses from the questions designed to obtain qualitative data was carried out for example; 'Have you noticed any change for your client in the use of taught skills, this could be an increase or decrease in their use?'.

5 Results

Related-samples Wilcoxon signed rank tests were carried out for all 18 questions (appendix G). The Wilcoxon signed rank test indicated that clients' ability to recognise feelings in any given situation was significantly higher at timepoint 2 ($p < 0.38$). This question sits within the emotion regulation subscale and was the only significant improvement found, across all 18 questions. A visual examination (graph 1) of this finding indicates a change in carers' rating. At time point one this indicated even distribution across the scale range (45.5% to 72.2%). At time point 2, ratings clustered at a single point (up to 40%). It is not possible to provide explanation for this change and is likely to be a statistical anomaly. The hypothesis that a beneficial change in skills used to regulate emotions will occur over time as a consequence of attending DBT skills groups can be rejected.

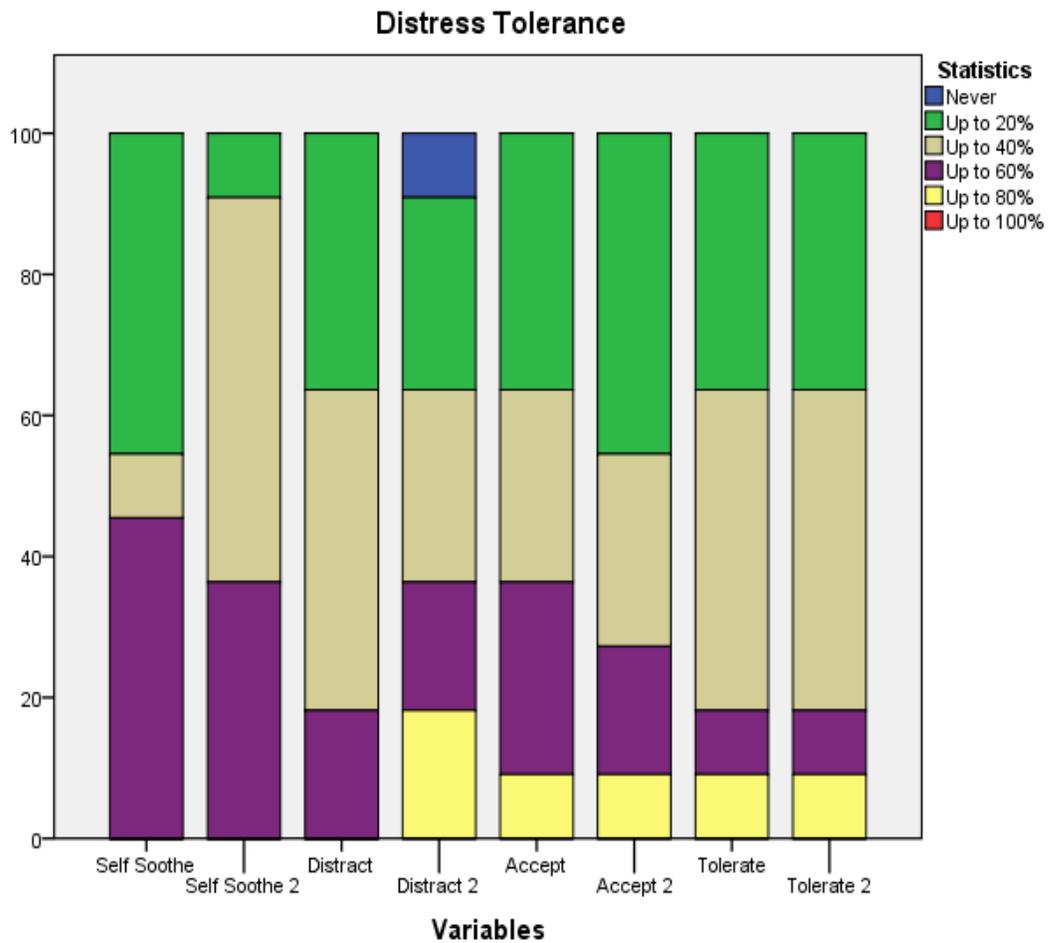
A visual inspection of the data did not reveal any obvious data trends to support the hypothesis. A review of the non-significant related-samples Wilcoxon signed rank test results identified only question 2 'Deliberately engaged in risky behaviour?' as close to being significant at (.083). This was one of the two closed questions that examined perceived change in self-harm. There were 13 completed responses to this qualitative question, five of which were supportive comments, for example; 'X has shown signs of improvement', and four were comments offering an alternative view, for example; 'I haven't noticed any change in the use of taught skills'. The remaining four responses were neutral or did not answer the question.

Graph 1: Changes in the use of Emotion Regulation skills across 2 time points.



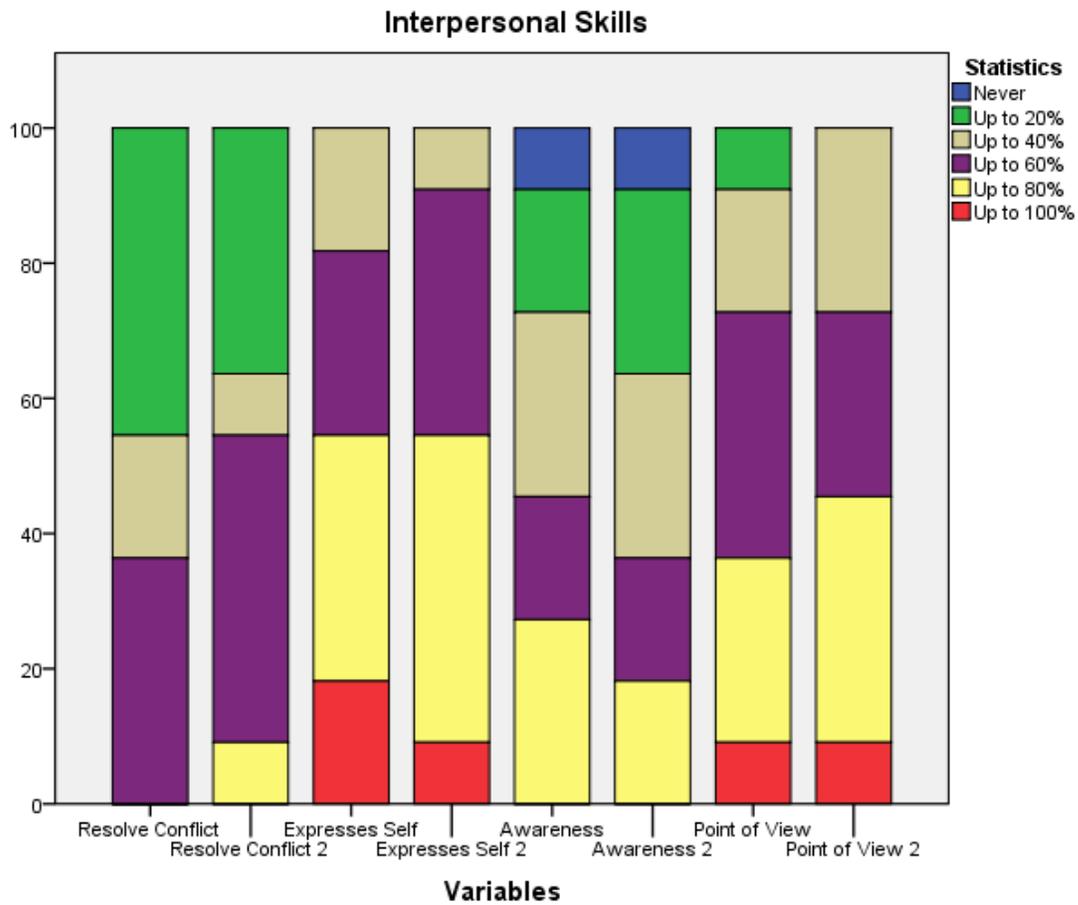
Graph 1; shows a greater number of clients were able to change their feelings up to 60% of the time, indicating an improvement on time point 1 ('change feelings' to 'change feelings 2').

Graph 2: Changes in the use of Distress Tolerance skills across 2 time points.



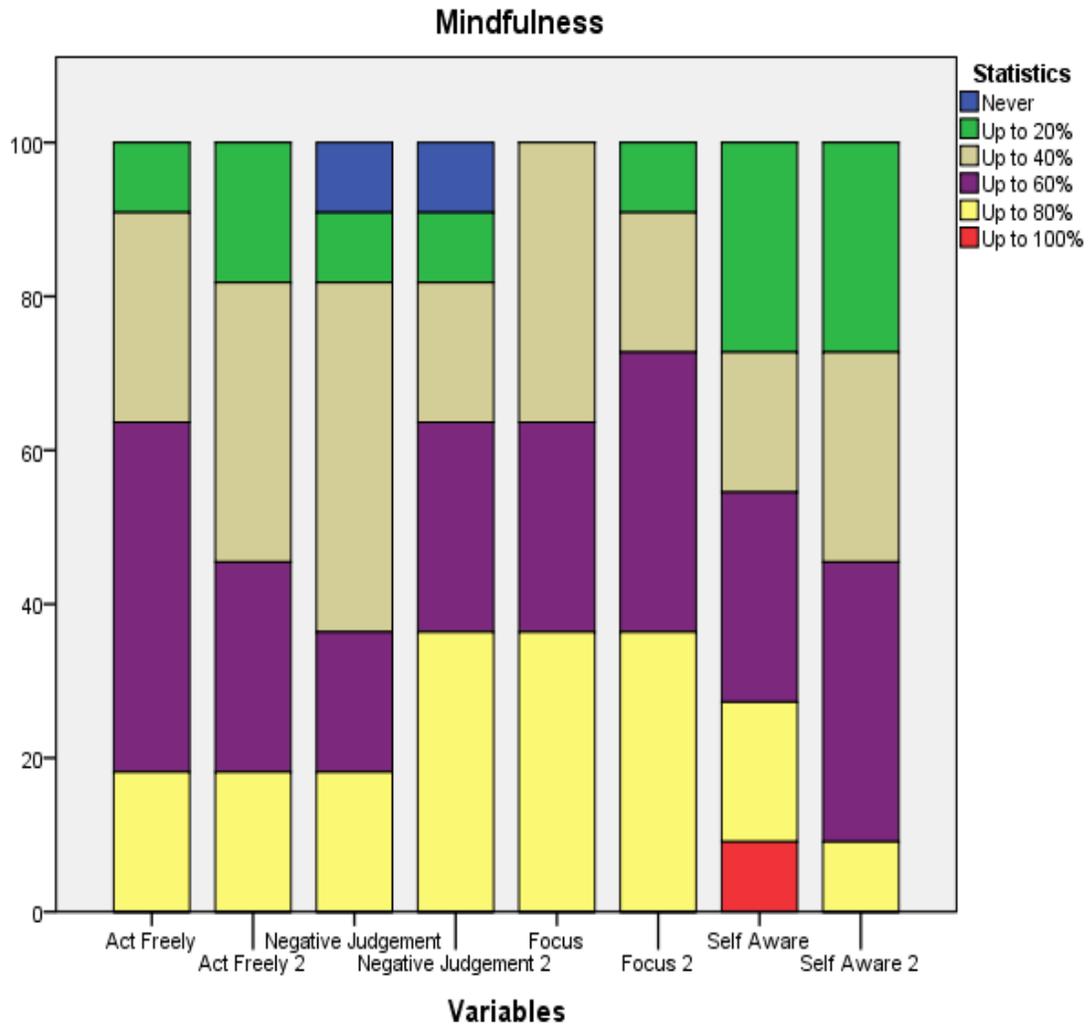
This graph shows that a greater number of clients were able to self soothe up to 40% of the time, or more frequently at time point 2 compared to 20% of the time at time point 1. Despite a small number of clients being less able to distract themselves at time point 2, some clients had improved to being able to distract themselves up to 80% of the time.

Graph 3: Changes in the use of Interpersonal skills across 2 time points.



This graph shows an increase in the client’s use of skills to resolve conflict, with more clients using this skill up to 60% of the time or more frequently. Overall, clients were also more likely to use skills aimed to help them express themselves.

Graph 4: Changes in the use of Mindfulness skills across 2 time points.



This graph shows a decrease in the clients' negative judgements.

6 Discussion

The purpose of this project was to evaluate the effectiveness of an existing community based DBT service for adults with intellectual disabilities. The aims of the project included an examination of the effectiveness of these services; an examination of the standard of the current service and to make contribution to the findings of the existing research.

A carer completed outcome measure questionnaire (DBT CFQ), developed by the service to examine perceived change in the use of four skills taught at a DBT skills group, was in use from 2012. Data extracted from the questionnaire between March 2012 and September 2015 was examined and resulted in the emergence of 11 sets of data identified as suitable to be used as pre and post measures to DBT skills training. Each set of data consisted of 18 questions measured at two points in time, which was subsequently analysed using SPSS. Related-samples Wilcoxon signed rank tests were carried out on all 18 questions across two time points resulting in only one significant finding. A visual examination of this finding provided no obvious explanation for this change and it is the understanding of the researcher that this was likely to be a statistical anomaly. An examination of the responses to the question designed to obtain qualitative data provided some anecdotal evidence of effectiveness but this is countered by several responses that are directly opposite to this position. The hypothesis that a beneficial change in skills used to regulate emotions will occur over time as a consequence of attending DBT skills groups for adults with intellectual disability received some anecdotal support but the primary finding of the project was that the hypothesis should be rejected. The results of this evaluation project mirror the evaluation outcomes from the existing literature; it offers no hard evidence for the effectiveness of this approach but offers some anecdotal evidence in support.

6.1 Limitations of Project

Although the project hypothesis has been rejected it is the view of the researcher that the primary reason for this outcome is a of lack research validity across the entire evaluation process. This opinion is based on a review of the four questions posed by Finger and Rand (2005) to examine research validity that is:

1. To what extent does the applied treatment accurately reflect the actual treatment under investigation?
2. To what extent are the conclusions drawn from the statistical analysis appropriate?
3. To what extent do the findings generalise two different settings or populations?
4. How reliable was the measurement validity?

The treatment delivered within the ID DBT service was an adapted version of the client skills group training developed by Linehan (1993). Adaptions included simplification of materials, extended treatment time and multiple repetitions of treatment; however, these adaptions closely adhered to the recommended treatment approach and were primarily extensions of time and simplifications of adherent DBT materials. A greater challenge to validity was as a consequence of the structure of the service delivery; each skills group was facilitated by three rotating members of the DBT service. These team members rotated in and out of the skills groups on a regular basis, had varied training backgrounds, lengths of experience and were of different professional groups. This service delivery model evolved for pragmatic reasons but resulted in significant variation in the treatment applied.

The researcher identified a number of concerns with regard to the sample analysis including the following. Firstly, the sample population examined adults with intellectual disabilities with severe emotion regulation difficulties, had only one client who met the diagnostic criteria for BPD and therefore was not representative of the client population that DBT was designed for. In addition, the evaluation of the presenting characteristics of the client participants revealed extreme variation (Table 1). Further, variability within the sample included the length of time individual clients were engaged in the service; differences in lengths of time between data collection at time point 1 and time point 2 and differing medication regimes affected the validity of results. Further concerns included maturation in that clients may have matured somewhat during their time attending therapy as a natural consequence of aging. A final variation was the attrition rate. A review carried out by the researcher (Baillie & Slater, 2014) identified a 40% dropout rate from the service. Often these clients have the most extreme presentations and as a result of their behaviour moved to placements out of county, others chose to leave the service therefore skewing the data. This may have resulted in ‘an illusory decline in mean’ (Finger & Rand, 2005, p. 17).

Ideally, a control group would have provided control for this variation, however, a decision was taken not to use a control group.. This decision was taken primarily for pragmatic and ethical reasons including the small number of participants available to the researcher. Allocation of clients to a control group within this service was also considered to be unethical as this would have deprived participants of a potentially beneficial treatment. In future consideration will be given to use of a waiting list control group.

In an effort to address some of these concerns a single group pre-test and post-test design was used as a design suitable for small group sizes and when the 'examination of within-subject changes is an explicit goal of the research' (Greenhoot, 2005, p. 94). This design also sheds light on the relationship between the independent and dependent variable; a pre-test enables an assessment of the initial samples internal equivalency (Greenhoot, 2005).

As a consequence of the significant variation within the sample evaluated and the unique nature of the service structure and treatment delivered. The findings of this project are unlikely to be generalised to other settings.

There are also concerns about the measure, the DBT CFQ, used within this evaluation piloted in 2012 as this was not a standardised tool and had not undergone assessment of its internal validity or reliability. In addition, carers completing the questionnaire were required to offer their subjective interpretations of client behaviour. It was not always possible to have the same carer complete the measure at each time point, meaning that changes observed may have been attributable to the carer's view of the client, rather than representing actual change (or lack of). The use of a single measure was also problematic in that the use of multiple measures would have increased the validity of any data obtained (Baillie & Slater, 2014)

A significant challenge to carrying out this evaluation was the size of the sample group available. The data was typically extracted from groups containing no more than five individuals.

The challenges to validity and analysis outlined above appear to replicate the experiences of other services delivering DBT to this population.

6.2 Clinical Implications

As the researcher currently provides the clinical leadership for the service under evaluation, the following recommendations are made for implementation within three months of its completion.

The process of data collection should be significantly revised; data should be collected at a fixed and consistent point in the process for each skills group; a commitment from the services that support clients to attend the service should be sought in order for a named worker to be identified to take responsibility for completing the questionnaires on an ongoing basis. To increase measurement validity pre-test data should be captured prior to the client attending skills group. Demographic information currently routinely collected and stored on the existing NHS electronic databases should be added to data collected by the service.

The service should carry out an urgent review of psychometric tools that might be used to evaluate outcomes and search for any ID standardised measures currently used to evaluate therapy that might be used to supplement the current outcome measures. Contact should be made with other DBT services that support clients with intellectual disabilities with a view of undertaking larger scale evaluations.

Consideration should be given to the use of alternative methods of evaluation for example single case methodology. It has been argued that this approach is ‘very useful for evaluating the effect

of an intervention with a specific client in an applied setting' (Anderson & Kim,2005, p. 73). The data collected for this type of evaluation could be inspected visually. This in turn would allow the researcher to determine if the outcome was both statistically and clinically significant. In addition, because of the real world challenges identified in carrying out quantitative research on the client population consideration should be given to the use of qualitative methodology

The service needs to give careful consideration to the makeup of group facilitators to ensure a consistency of experience and knowledge when delivering skills groups.

In addition to the measures described previously a development session will be scheduled, dedicated to a review of the current service evaluation process.

7 Critical Appraisal

A key component of the psychologist's role (BPS, 2011) is conducting clinical research. Undertaking this service evaluation has provided the researcher with practical insight into the shortcomings of the evaluation approach used with the service. It is evident from process and outcomes of this project that the researcher has paid insufficient attention to the practical and methodological issues that arise when properly designing a service evaluation approach.

The researcher has reflected on this situation and believes that insufficient time and attention has been allocated by those involved in the service to this task. The primary focus of the service has been on clinical intervention, but the question that remains is whether this effort is worthwhile from a clients' perspective. The researcher is committed to the practice of DBT as a model of

therapy and has little doubt about its effectiveness from a personal point of view. This personal bias has resulted in neglecting to evaluate DBT. This project has resulted in a 'wake-up call' for the researcher and as such has been very useful. The evaluation has highlighted the genuine challenges of under-taking this process effectively in a community health setting. The researcher intends to ensure that sufficient energy and time is allocated to the service evaluation process in the future.

8 Conclusion

This evaluation found only a small amount of descriptive evidence to support its hypothesis that a beneficial change in skills used to regulate emotions would occur over time as a consequence of attending DBT skills groups for adults with intellectual disability. It is the researcher opinion that the primary reason for this outcome is a lack of research validity across the entire evaluation process. The main benefit of this evaluation has been the scrutiny and critique of the ID DBT service current evaluation methodology and the recommendations made.

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Section 5: Appendices

Appendix A: Topic Guides For Focus Groups

Focus group questions for therapists **Version 1** 20/08/2013

- 1) Please could you tell me how you came to be part of the DBT service?
- 2) What did expect working in a DBT service to be like?
- 3) Please could you tell me about the work that you do?
- 4) Could you tell me about your best experience as a DBT therapist/facilitator?
- 5) Could you tell me about your worst experience as a DBT therapist/facilitator?
- 6) What impact do you think DBT has on those you work with?

Focus group questions for carers **Version 1**

- 1) Please could you tell me how you came to be part of the carers group?
- 2) What did expect participating in the carers group would be like?
- 3) Could you tell me about your best experience as a carer group member?
- 4) Could you tell me about your worst experience as a carer group member?
- 5) What impact do you think DBT has on those you work with?
- 6) What impact do you think attending carers group has had on you?

Focus group questions for clients **Version 1**

- 1) Please could you tell me how you came to be part of the DBT?
- 2) What did expect DBT to be like?
- 3) Could you tell me about the best time you have had in DBT?
- 4) Could you tell me about the worst time you have had in DBT?
- 5) What have got from coming to DBT?
- 6) What difference has it made to your life?

Appendix B: Approval Letters



Health Research Authority

NRES Committee London - Brent

80 London Road
Skipton House
London
SE1 6LH

Telephone: 020 7972 2567
Facsimile: 020 7972 2592

08 October 2013

Mr Sean Liam Slater



Dear Mr Slater

Study title: Developing an understanding of the impact of DBT on adults with a learning disability with emotion regulation difficulties.
REC reference: 13/LO/1038
IRAS project ID: 103826

Thank you for your letter of 01 October 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Nischinth Cherodian, NRESCommittee.SECoast-BrightonandSussex@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/LO/1038

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr John Keen
Chair

Email: NRESCommittee.SECOast-BrightonandSussex@nhs.net

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Dr Steve Melluish
Dr Peter Wilson, Wye Valley NHS Trust

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		18 June 2013
Letter of invitation to participant	1	18 June 2013
Other: summary CV for supervisor		19 June 2013
Other: Topic guides for discussions	1	01 October 2013
Other: CV for Mr Aubrey Baillie		01 October 2013
Participant Consent Form	1	18 June 2013
Participant Consent Form: for clients	2	01 October 2013
Participant Consent Form: for therapists	2	01 October 2013
Participant Consent Form: for clients	2	01 October 2013
Participant Information Sheet	1	18 June 2013
Participant Information Sheet: for clients	2	01 October 2013
Participant Information Sheet: for carers	2	01 October 2013
Participant Information Sheet: for therapists	2	01 October 2013
Protocol		18 June 2013
REC application		18 June 2013
Response to Request for Further Information		01 October 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Our R&D ref: 13/026/2gt

Friday, 15 November 2013

Sean Slater
Head of Learning Disability Psychology

Dear Mr. Slater,

Study title: Developing an Understanding of the Impact of DBT on adults with a learning disability with emotion regulation
IRAS Project ID: 103826
REC reference: 13/LO/1038

Thank you for forwarding information on the above study. I can confirm the approval of [redacted] Foundation Trust for the above study to proceed.

Your project will now be added to the Gloucestershire Health Community Research Register which will identify the following:

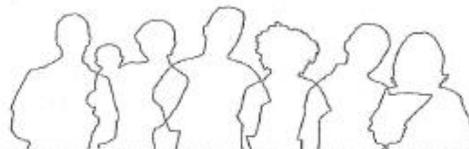
- Chief Investigator: **Mr. Sean Slater**
- Sponsoring Organisation: **University of Leicester**
- Host Organisation: [redacted] Trust
- Type of Study: **Qualitative**

It is important that all research conducted with NHS patients and/or staff complies with the Research Governance Framework. In relation to this I would like to take the opportunity to remind you of some of your responsibilities under this framework.

1. **Health and safety:** You are reminded of your responsibilities for health and safety at work under the Health and Safety at Work Act 1974. You have a legal responsibility to take care of your own and

Chair: Professor Clair Chilvers DSc
Chief Executive: Dr Frank Harsent PhD, MBA

www.gloshospitals.nhs.uk



BETTER FOR YOU

other people's Health and Safety at work under the Health and Safety at Work ACT 1974 as amended and associated legislation. These include the duty to take reasonable care to avoid injury to yourself and to others by your work activities or omissions, and to co-operate with your employer in the discharge of its statutory duties. You must adhere strictly to the policies and procedures on health and safety.

2. **Codes of confidentiality/Data Protection:** Anybody who records patient information (whether on paper or by electronic means) has a responsibility to take care to ensure that the data recorded is accurate, timely and as complete as possible. It is vital that you conduct your research in accordance with the principles of the Data Protection Act 1998 and codes of confidentiality.
3. **Liability and Indemnity:** Indemnity for your study will be as described in any applicable Clinical Trial Agreement or other Research Contract.
Where such an agreement is not available, the Trust will indemnify its employees and researchers holding NHS Honorary Contracts for the purposes of Negligent Harm.
NHS Trusts cannot provide cover for No Fault or Non-Negligent claims. Where this is required, it is expected that the Research Sponsor will provide such indemnity.
4. **Intellectual Property:** Intellectual Property is defined as the tangible output of any intellectual activity that is new or previously undescribed. It can include the following:
 - i. Inventions, such as new medical devices, software;
 - ii. Literary works, such as software, patient leaflets, journal articles;
 - iii. Designs and drawings, such as posters, leaflets;
 - iv. Brand names, such as logos and trademarks; and
 - v. Trade secrets, such as surgical techniques.

For projects originating from outside of the NHS Trust with which this agreement is made, Intellectual Property rights will remain with the Lead Site/Investigator unless developed from observations made outside of the scope and influence of the project. The rights to Intellectual Property generated in such a fashion will remain with the Host Trust unless an agreement to the contrary has been signed by both parties. Where a Clinical Trial Agreement or other Contract exists, this will take priority over this clause.

5. **Adverse Events/Incidents:** Any adverse events you witness or suspect to have happened *must* be reported to your supervisor or manager as soon as you know about them and dealt with as described in the research protocol.
6. **Fraud and Misconduct:** Any suspicions of active fraud or misconduct *must* be reported to your supervisor or manager immediately and will be treated in the strictest confidence. The monitoring of research will also seek to reduce incidents of research misconduct and fraud.
7. **Monitoring:** As part of the Research Governance Framework, during the course of your research you may be monitored to ensure that procedures in the protocol approved by the ethics committee are being adhered to. For locally sponsored studies this will be undertaken by the R&D Office. For externally sponsored studies this is likely to be arranged by the appropriate sponsor.
8. **Dissemination:** The Framework also requires the dissemination of research findings to the research subjects, NHS staff and the public. On completion of your research you will be expected to produce a summary of the project and an indication of how the results from the study will be disseminated. For studies where publication of research results is not the responsibility of the local Investigator, requests for such information will be made to the sponsor.
9. **Termination of Agreement:** The Trust also reserve the right to terminate the agreement for your research to proceed if, at any time, you are found to be in breach of the clauses in this Approval Letter or fail to adequately meet the requirements of the Research Governance Framework.

If you need any further support or information, please do not hesitate to contact us at the above address, quoting our reference number for your study.

I wish you every success with your project

Yours sincerely, 


**Senior Research & Development Manager
(Gloucestershire R&D Consortium)**



Cc via email:


Appendix C: Information Sheets and Consent Forms

Patient Information Sheet for Clients

Version 2

This information will be communicated to clients in association with a specialist LD speech and language therapist.

Purpose of the Study: The purpose of the study is to explore and better understand the experience of people with a learning disability receiving Dialectical Behaviour Therapy (DBT).

What will the study involve? The study will involve spending up to one hour talking with other therapists about your personal experience of participating in DBT. This will be called a focus group session.

Why have you been asked to take part? You have been asked because you have been receiving DBT therapeutic sessions.

Do you have to take part? The answer is No, participation is voluntary. I will explain the study 2 weeks before you attend the focus group session and on the day of the group session. On each occasion I will make sure that you fully understand and are happy to participate. On the day of the group session I will also ask you to sign a consent form to obtain your written agreement to participation. You will have the option of withdrawing your consent even if you have agreed to participate and can leave the study before it commences and up to 2 weeks after the group session has been held and until the time that all data has been collected and its analyses commenced by the researcher. All information collected will be totally anonymised so that no individual who has participated in the study can be identified. After the data has been analysed any identifiable information held by the researcher will be destroyed.

Will your participation in the study be kept confidential? The researcher or his associates will not share any information that could lead to the identification of participants and will anonymise the data so that no clues to your identity will appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

What will happen to the information which you give? The data will be kept confidentially for the duration of the study. On completion of the thesis, it will be retained for a further six months and then destroyed.

What will happen to the results? The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course. The study may be published in a research journal.

What are the possible disadvantages of taking part? I don't envisage any negative consequences for you in taking part. It is possible that talking about your experience in this way may cause you some distress.

What if there is a problem? At the end of the group session, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, I or your own

therapist will provide support in a 1:1 session or you can call the DBT team or receive support in the skill's group.

Who has reviewed this study? The National Research Ethics Service.

Any further queries? If you need any further information, you can contact me: Sean Slater

[REDACTED]

If you agree to take part in the study, please sign the consent form overleaf

Purpose of the Study; The purpose of the study is explore with carers' of people with a learning disability their experience of participating in a DBT carers' group.

What will the study involve? The study will involve spending up to one hour talking with other carers about your personal experience of participating in a DBT carers group. This will be called a focus group session.

Why have you been asked to take part? You have been asked because you have been participating in a DBT carers' group.

Do you have to take part? The answer is No, participation is voluntary. I will explain the study 2 weeks before you attend the focus group session and on the day of the group session. On each occasion I will make sure that you fully understand and are happy to participate. On the day of the group session I will also ask you to sign a consent form to obtain your written agreement to participation. You will have the option of withdrawing your consent even if you have agreed to participate and can leave the study before it commences and up to 2 weeks after the group session has been held and until the time that all data has been collected and its analyses commenced by the researcher. All information collected will be totally anonymised so that no individual who has participated in the study can be identified. After the data has been analysed any identifiable information held by the researcher will be destroyed.

Will your participation in the study be kept confidential? The researcher or his associates will not share any information that could lead to the identification of participants and will anonymise the data so that no clues to your identity will appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

What will happen to the information which you give? The data will be kept confidentially for the duration of the study. On completion of the thesis, it will be retained for a further six months and then destroyed.

What will happen to the results? The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course. The study may be published in a research journal.

What are the possible disadvantages of taking part? I don't envisage any negative consequences for you in taking part. It is possible that talking about your experience in this way may cause you some distress.

What if there is a problem? At the end of the group session, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, I will support you with this either in a 1:1 session or you can receive support in the cares group.

Who has reviewed this study? The National Research Ethics Service.

Any further queries? If you need any further information, you can contact me: Sean Slater

If you agree to take part in the study, please sign the consent form overleaf.

Information Sheet for Therapists

Purpose of the Study;

The purpose of the study is to explore with therapists their experience of the application of DBT with a learning disability client group;

What will the study involve? The study will involve spending up to one hour talking with other therapists about your personal experience of the application of DBT. This will be called a focus group session.

Why have you been asked to take part? You have been asked because you have been delivering DBT therapeutic sessions.

Do you have to take part? The answer is No, participation is voluntary. I will explain the study 2 weeks before you attend the focus group session and on the day of the group session. On each occasion I will make sure that you fully understand and are happy to participate. On the day of the group session I will also ask you to sign a consent form to obtain your written agreement to participation. You will have the option of withdrawing your consent even if you have agreed to participate and can leave the study before it commences and up to 2 weeks after the group session has been held and until the time that all data has been collected and its analyses commenced by the researcher. All information collected will be totally anonymised so that no individual who has participated in the study can be identified. After the data has been analysed any identifiable information held by the researcher will be destroyed.

Will your participation in the study be kept confidential? The researcher or his associates will not share any information that could lead to the identification of participants and will anonymise the data so that no clues to your identity will appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

What will happen to the information which you give? The data will be kept confidentially for the duration of the study. On completion of the thesis, it will be retained for a further six months and then destroyed.

What will happen to the results? The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course. The study may be published in a research journal.

What are the possible disadvantages of taking part? I don't envisage any negative consequences for you in taking part. It is possible that talking about your experience in this way may cause you some distress.

What if there is a problem? At the end of the group session, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, I will support you with this either in a 1:1 session or you can receive support in the therapist's consultation group.

Who has reviewed this study? The National Research Ethics Service.

Any further queries? If you need any further information, you can contact me: Sean Slater

If you agree to take part in the study, please sign the consent form overleaf.

Appendix D: Initial Coding Stage Of IPA

Emergent Themes	Original Transcript Therapist - Page 6	Exploratory Comments
	Therapist 4:	
DBT requires effort (hard work)	<i>"I trained with [Facilitator] in another team and very aware that there's lots of hard work being done sort of psychologically and academically and also for me there was something about the group gelling and doing things their own way and me coming in as a new person to that it took me a while for me to kind of be comfortable with that process, um and to feel sort of part of it um because I was not part of the initial setting up of it. So for me that's where some of the work has been and I have..."</i>	T4 highlighted her prior relationship with the Focus group facilitator. T4 emphasized the amount of hard work required to establish a new service "Also from me there was something about the group gelling and doing things their own way and me coming in as a new person to that it took me a while for me to kind of be comfortable" T4 also reported being anxious about being a new member joining a group –as she had not been an original member of the service "I was not part of the initial setting up of it" Internal thinking about self – I worked hard to become a member of the service. "so for me that's where some of the work has been"
Anxious about personal performance		
DBT requires effort (hard work)		
	[Facilitator]:	
Previous efforts unsuccessful	<i>"Because I was part, obviously I was here for its inception in this locality that I trained previously and but, but a bit like you [Therapist 2] it was based on a struggle I'd had working with... um... a client with an intellectual disability with description of borderline personality disorder and so that's part of why I wanted to... um... be... develop the initiative of having a DBT service locally."</i>	Facilitator - Internal thinking about self – struggled to be effective when working with this client group. "but a bit like [Therapist 2] it was based on a struggle I had working with a client with an intellectual disability with description of borderline personality disorder" "so that part of why I wanted, B, developed the initiative of having a DBT service locally" Event - previous perceived failures - motivated the facilitator to develop a local service.
Loss of self esteem		
wanted change		

Appendix E: Summary of protocol for using IPA with focus group data

Step 1: Objects of Concern and Experiential Claims	<p>Pick out experiential claims and concerns as they appear in the transcript.</p> <p>Summarise these, and sort into emergent patterns.</p>
Step 2: Positionality	<p>Explore the role played by facilitators, keeping track of questions, permissions, encouragements, redirections, etc. What is their perspective, stance, position?</p> <p>Explore the function of statements made by respondents. What is their perspective, stance?</p>
Step 3: Roles & Relationships	<p>Examine references to other people. What roles and relationships are described? What sorts of meanings and expectations are attributed to these relationships?</p> <p>What are understood to be the consequences of these?</p>
Step 4: Organisations & Systems	<p>Examine references to organisations and systems: How are they described? What sorts of meanings and expectations are attributed to these?</p> <p>What are understood to be the consequences of these?</p>
Step 5: Stories	<p>Examine the stories told by participants: look at the structure; genre; imagery and tone. What does each story achieve? How do participants support or impede each other to share their experiences? What temporal referents exist?</p>
Step 6: Language	<p>Throughout stages 1–5, monitor language use, paying particular attention to use of metaphor, euphemism, idiom, etc. Consider:</p> <p><i>a. Patterns</i></p> <p>Repetition, jargon, stand-out words and phrases, turn-taking, prompting – are these identified in individuals or the whole group?</p> <p><i>b. Context</i></p> <p>Impact on language used; descriptions of feelings/emotive language; jargon and explanation of</p>

	<p>technical terms; impact of facilitator.</p> <p><i>c. Function</i></p> <p>How/why is certain language being used? (e.g. to emphasize/back-up a point, to shock, to provoke (dis)agreement, to amuse/lighten the tone?)</p>
<p>Step 7: Adaptation of Emergent Themes</p>	<p>Return to the emergent themes from step 1 and adapt them according to the work done subsequently. Answering the following questions will help:</p> <p>a. What experiences are being shared?</p> <p>b. What are individuals doing by sharing their experiences?</p> <p>c. How are they making those things meaningful to one another?</p> <p>d. What are they doing as a group?</p> <p>e. What are the consensus issues?</p> <p>f. Where is there conflict? How is this being managed/resolved?</p>
<p>Step 8: Integration of Multiple Cases</p>	<p>Where more than one focus group has taken place, integrate work done with each to build up an overall analysis of the topic under investigation. Data should be checked to ensure sufficient homogeneity between focus groups to allow for successful integration. To draw the analysis to completion:</p> <p>a. Pick out commonalities and stand-out differences between groups drawing out superordinate themes.</p> <p>b. Frequently revisit the transcripts to check themes in relation to original claims made to help ensure accuracy.</p>

Appendix F: DBT Carer Feedback Questionnaire

Client's name: _____ Rated by: _____

Date: _____

- A. Please rate the extent to which _____ has done the following over the **past four weeks** by circling the appropriate number on each scale:

1. Is able soothe themselves when distressed (when needed)

0	1	2	3	4	5
-----	-----	-----	-----	-----	-----
Never	Up to 20% of the time	Up to 40% of the time	Up to 60% of the time	Up to 80% of the time	Up to 100% of the time

2. Is able to resolve conflicts with other people (when needed)

0	1	2	3	4	5
-----	-----	-----	-----	-----	-----
Never	Up to 20% of the time	Up to 40% of the time	Up to 60% of the time	Up to 80% of the time	Up to 100% of the time

3. Is overwhelmed by feelings

0	1	2	3	4	5
-----	-----	-----	-----	-----	-----
Never	Up to 20% of the time	Up to 40% of the time	Up to 60% of the time	Up to 80% of the time	Up to 100% of the time

4. Is able to express themselves appropriately to get what they want (when needed)

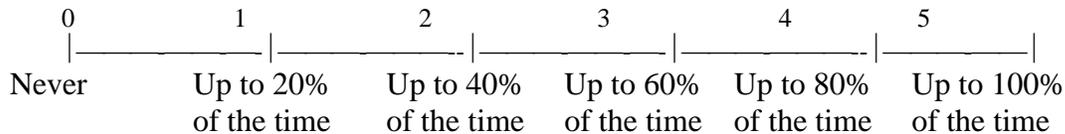
0	1	2	3	4	5
-----	-----	-----	-----	-----	-----
Never	Up to 20% of the time	Up to 40% of the time	Up to 60% of the time	Up to 80% of the time	Up to 100% of the time

5. Shows awareness of other people's needs (when needed)

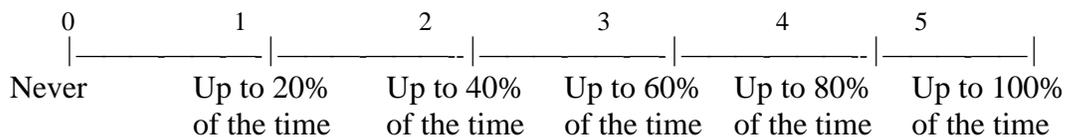
0	1	2	3	4	5
-----	-----	-----	-----	-----	-----
Never	Up to 20% of the time	Up to 40% of the time	Up to 60% of the time	Up to 80% of the time	Up to 100% of the time

Please rate the extent to which _____ has done the following over the **past four weeks** by circling the appropriate number on each scale:

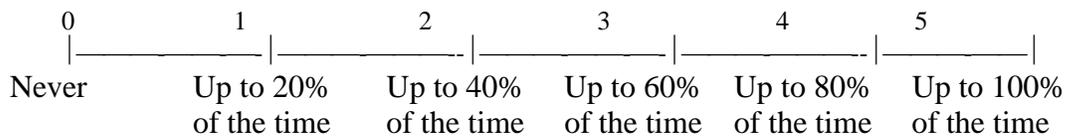
6. Is able to express their feelings appropriately (when needed)



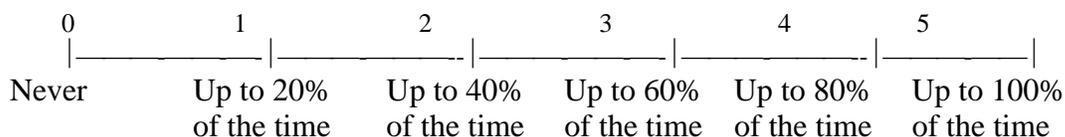
7. Is able to get their point of view taken seriously (when needed)



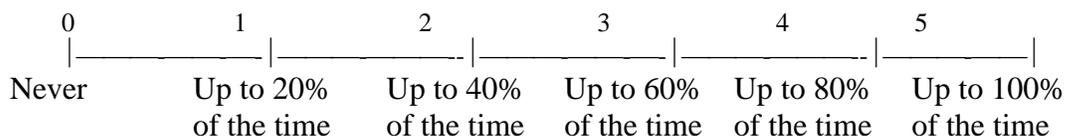
8. Is able to act freely and effectively in the moment (when needed)



9. Is able to distract themselves when distressed (when needed)

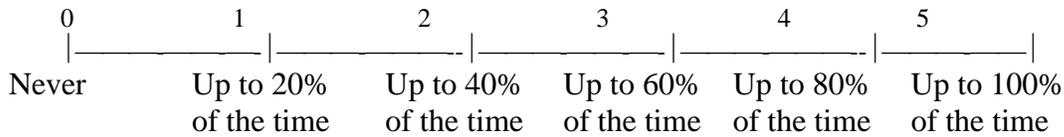


10. Makes negative judgements about themselves

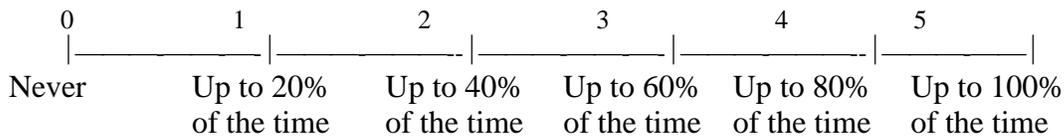


Please rate the extent to which _____ has done the following over the **past four weeks** by circling the appropriate number on each scale:

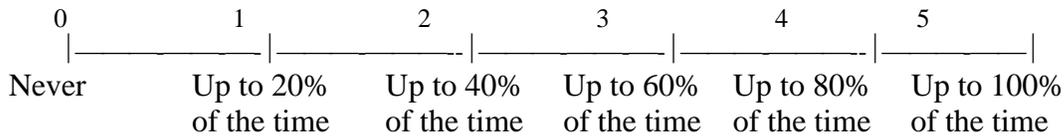
11. Is able to focus on what they're doing (when needed)



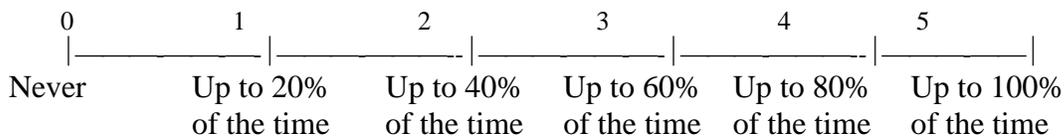
12. Recognises how they feel in any given situation (when needed)



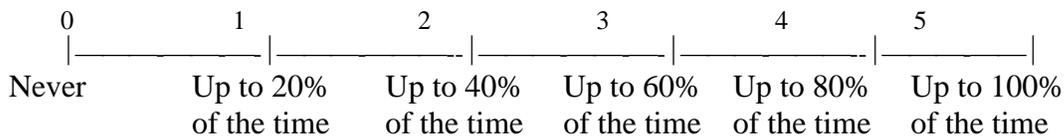
13. Is able to change the way they feel when distressed (when needed)



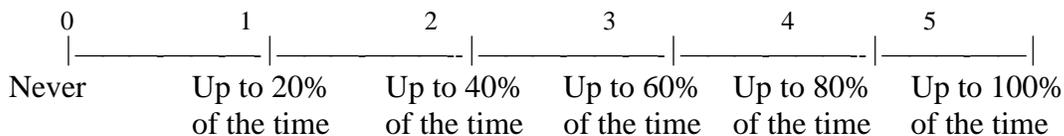
14. Is inhibited and self-conscious



15. Is able to accept things not going their way (when needed)



16. Is able to tolerate their own negative feelings (when needed)



Have you noticed any change for your client in the use of taught skills this could be an increase or decrease of their use? *Please circle the appropriate answer*

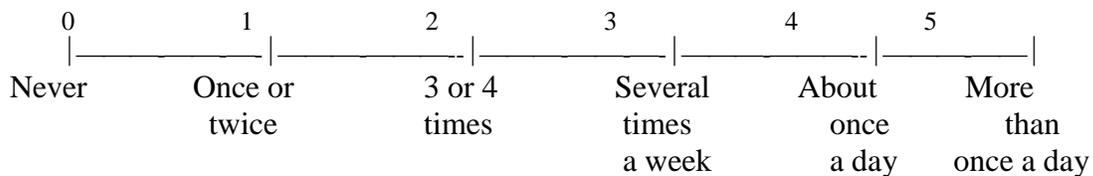
- a) Being focused: **YES or NO**
- b) Distress Tolerance e.g. self soothing or distraction: **YES or NO**
- c) Emotion Regulation e.g. identify and managing emotions: **YES or NO**
- d) Being effective in relationships: **YES or NO**

Please write in your own words specific examples (indicating type of skill):

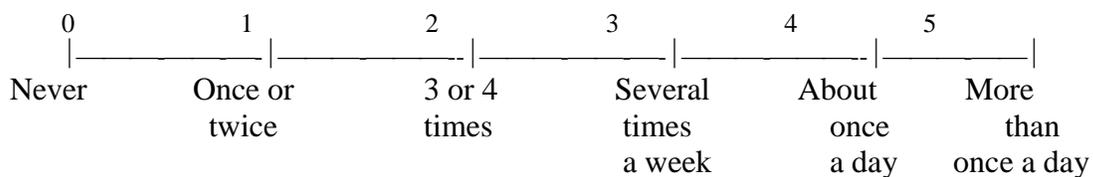
Self-Harming: Has _____ done any of the following during the past 4 weeks?

Please circle the appropriate number

1. Physically hit or cut themselves deliberately?



2. Deliberately engaged in risky behaviour? e.g. with the result they get arrested; get assaulted; get hurt in some way, gets so drunk it interferes with daily activities



If they have: *please write in what they did:*

Appendix G. Wilcoxon Data

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Self Soothe and Self Soothe 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.257	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Resolve Conflict and Resolve Conflict 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.336	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Overwhelmed and Overwhelmed 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.763	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Expresses Self and Expresses Self 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	1.000	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Awareness and Awareness 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.480	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Express Feelings and Express Feelings 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.886	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Point of View and Point of View 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.414	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Act Freely and Act Freely 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.257	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Distract and Distract 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.558	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Negative Judgement and Negative Judgement 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.285	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Focus and Focus 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	1.000	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Recognise Feelings and Recognise Feelings 2 equals 0.	Related- Samples Wilcoxon Signed Rank Test	.038	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Change Feelings and Change Feelings 2 equals 0.	Related- Samples Wilcoxon Signed Rank Test	.490	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Self Aware and Self Aware 2 equals 0.	Related- Samples Wilcoxon Signed Rank Test	.429	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Accept and Accept 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.480	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Tolerate and Tolerate 2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	1.000	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Physcut1 and Physcut2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.564	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between RiskyBeh1 and Riskybeh2 equals 0.	Related-Samples Wilcoxon Signed Rank Test	.083	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Appendix H: Statement of Epistemological Position

The epistemological stance chosen for this research was a critical realism perspective and this is outlined briefly within the main research paper. This statement is intended to supplement that outline.

Critical realism is a form of post-positivist epistemology. Positivists' take an empirical stance towards scientific endeavour, viewing the experiment as the key approach to scientific method. The experiment is a test under controlled conditions to examine the validity of a hypothesis in which the scientist observes the relationship between cause and effect and imposes meaning on the outcome. In the mid to late 20th century there was a move away from positivism, particularly in social science, to post-positivism (Bhaskar, 1975; 1993 & 1998). Post-positivism acknowledges that theories, context, theoretical knowledge and the personal values of the researcher can influence the interpretation of what is observed. That is not to say that post-positivists do not pursue objectivity but do so while acknowledging the possible effects of biases (Robson, 2002). Post-positivist therefore emphasises the importance of multiple measures and observations, acknowledging each may possess different types of error. A critical realist believes that a reality exists that is independent of that which can be observed for example feelings . The understanding of this reality is shaped by subjectivity and social forces and it can be studied (Guba and Lincoln, 1994). It is the researchers' opinion that when carrying out research, this philosophical stance and its implications need to be considered.

References:

Bhaskar, R., (1975). *A Realist Theory of Science: 2nd edition*, (London, Verso).

Bhaskar, R., (1993). *Dialectic: The Pulse of Freedom*, (London, Verso).

Bhaskar, R., (1998). *The Possibility of Naturalism: A Philosophical Critique of the Contemporary Human Sciences: Third Edition*, (London, Routledge).

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). London: Sage.

Ronson, C. (2002). *Real World Research. A resource for Social Scientists and Practitioner Researchers (Second Edition)*. Malden: Blackwell.

Appendix I: Guidelines for Admissions to the Journal of Mental Health and Intellectual Disabilities

Format	Article files should be provided in Microsoft Word format. LaTeX files can be used if an accompanying PDF document is provided. PDF as a sole file type is not accepted, a PDF must be accompanied by the source file. Acceptable figure file types are listed further below.
Article Length	Articles should be between 3000 and 6000 words in length. This includes all text including references and appendices. Please allow 350 words for each figure or table.
Article Title	A title of not more than eight words should be provided.
Author details	<p>All contributing authors' names should be added to the ScholarOne submission, and their names arranged in the correct order for publication.</p> <ul style="list-style-type: none"> • Correct email addresses should be supplied for each author in their separate author accounts • The full name of each author must be present in their author account in the exact format they should appear for publication, including or excluding any middle names or initials as required • The affiliation of each contributing author should be correct in their individual author account. The affiliation listed should be where they were based at the time that the research for the paper was conducted
Biographies and acknowledgements	Authors who wish to include these items should save them together in an MS Word file to be uploaded with the submission. If they are to be included, a brief professional biography of not more than 100 words should be supplied for each named author.
Research funding	Authors must declare all sources of external research funding in their article and a statement to this effect should appear in the Acknowledgements section. Authors should describe the role of the funder or financial sponsor in the entire research process, from study design to submission.
Structured Abstract	<p>Authors must supply a structured abstract in their submission, set out under 4-7 sub-headings (see our "How to... write an abstract" guide for practical help and guidance):</p> <ul style="list-style-type: none"> • Purpose (mandatory) • Design/methodology/approach (mandatory) <ul style="list-style-type: none"> • Findings (mandatory) • Research limitations/implications (if applicable) <ul style="list-style-type: none"> • Practical implications (if applicable) • Social implications (if applicable)

- Originality/value (mandatory)

Maximum is 250 words in total (including keywords and article classification, see below).

Authors should avoid the use of personal pronouns within the structured abstract and body of the paper (e.g. "this paper investigates..." is correct, "I investigate..." is incorrect).

Keywords

Authors should provide appropriate and short keywords in the ScholarOne submission that encapsulate the principal topics of the paper (see the [How to... ensure your article is highly downloaded](#) guide for practical help and guidance on choosing search-engine friendly keywords). The maximum number of keywords is 12.

Whilst Emerald will endeavour to use submitted keywords in the published version, all keywords are subject to approval by Emerald's in house editorial team and may be replaced by a matching term to ensure consistency.

Article Classification

Authors must categorize their paper as part of the ScholarOne submission process. The category which most closely describes their paper should be selected from the list below.

Research paper. This category covers papers which report on any type of research undertaken by the author(s). The research may involve the construction or testing of a model or framework, action research, testing of data, market research or surveys, empirical, scientific or clinical research.

Viewpoint. Any paper, where content is dependent on the author's opinion and interpretation, should be included in this category; this also includes journalistic pieces.

Technical paper. Describes and evaluates technical products, processes or services.

Conceptual paper. These papers will not be based on research but will develop hypotheses. The papers are likely to be discursive and will cover philosophical discussions and comparative studies of others' work and thinking.

Case study. Case studies describe actual interventions or experiences within organizations. They may well be subjective and will not generally report on research. A description of a legal case or a hypothetical case study used as a teaching exercise would also fit into this category.

Literature review. It is expected that all types of paper cite any relevant literature so this category should only be used if the main purpose of the paper is to annotate and/or critique the literature in a particular subject area. It may be a selective bibliography providing advice on information sources or it may be comprehensive in that the paper's aim is to cover the main contributors to the development of a topic and explore their different views.

General review. This category covers those papers which provide an overview or

	historical examination of some concept, technique or phenomenon. The papers are likely to be more descriptive or instructional ("how to" papers) than discursive.
Headings	<p>Headings must be concise, with a clear indication of the distinction between the hierarchy of headings.</p> <p>The preferred format is for first level headings to be presented in bold format and subsequent sub-headings to be presented in medium italics.</p>
Notes/Endnotes	Notes or Endnotes should be used only if absolutely necessary and must be identified in the text by consecutive numbers, enclosed in square brackets and listed at the end of the article.
Figures	<p>All Figures (charts, diagrams, line drawings, web pages/screenshots, and photographic images) should be submitted in electronic form.</p> <p>All Figures should be of high quality, legible and numbered consecutively with arabic numerals. Graphics may be supplied in colour to facilitate their appearance on the online database.</p> <ul style="list-style-type: none"> • Figures created in MS Word, MS PowerPoint, MS Excel, Illustrator should be supplied in their native formats. Electronic figures created in other applications should be copied from the origination software and pasted into a blank MS Word document or saved and imported into an MS Word document or alternatively create a .pdf file from the origination software. • Figures which cannot be supplied as above are acceptable in the standard image formats which are: .pdf, .ai, and .eps. If you are unable to supply graphics in these formats then please ensure they are .tif, .jpeg, or .bmp at a resolution of at least 300dpi and at least 10cm wide. • To prepare web pages/screenshots simultaneously press the "Alt" and "Print screen" keys on the keyboard, open a blank Microsoft Word document and simultaneously press "Ctrl" and "V" to paste the image. (Capture all the contents/windows on the computer screen to paste into MS Word, by simultaneously pressing "Ctrl" and "Print screen".) • Photographic images should be submitted electronically and of high quality. They should be saved as .tif or .jpeg files at a resolution of at least 300dpi and at least 10cm wide. Digital camera settings should be set at the highest resolution/quality possible.
Tables	<p>Tables should be typed and included in a separate file to the main body of the article. The position of each table should be clearly labelled in the body text of article with corresponding labels being clearly shown in the separate file.</p> <p>Ensure that any superscripts or asterisks are shown next to the relevant items and have corresponding explanations displayed as footnotes to the table, figure or plate.</p>
References	References to other publications must be in Harvard style and carefully checked for completeness, accuracy and consistency. This is very important in an

electronic environment because it enables your readers to exploit the Reference Linking facility on the database and link back to the works you have cited through CrossRef.

You should cite publications in the text: (Adams, 2006) using the first named author's name or (Adams and Brown, 2006) citing both names of two, or (Adams *et al.*, 2006), when there are three or more authors. At the end of the paper a reference list in alphabetical order should be supplied:

<i>For books</i>	Surname, Initials (year), <i>Title of Book</i> , Publisher, Place of publication. e.g. Harrow, R. (2005), <i>No Place to Hide</i> , Simon & Schuster, New York, NY.
<i>For book chapters</i>	Surname, Initials (year), "Chapter title", Editor's Surname, Initials, <i>Title of Book</i> , Publisher, Place of publication, pages. e.g. Calabrese, F.A. (2005), "The early pathways: theory to practice – a continuum", in Stankosky, M. (Ed.), <i>Creating the Discipline of Knowledge Management</i> , Elsevier, New York, NY, pp. 15-20.
<i>For journals</i>	Surname, Initials (year), "Title of article", <i>Journal Name</i> , volume issue, pages. e.g. Capizzi, M.T. and Ferguson, R. (2005), "Loyalty trends for the twenty-first century", <i>Journal of Consumer Marketing</i> , Vol. 22 No. 2, pp. 72-80.
<i>For published conference proceedings</i>	Surname, Initials (year of publication), "Title of paper", in Surname, Initials (Ed.), <i>Title of published proceeding which may include place and date(s) held</i> , Publisher, Place of publication, Page numbers. e.g. Jakkilinki, R., Georgievski, M. and Sharda, N. (2007), "Connecting destinations with an ontology-based e-tourism planner", in <i>Information and communication technologies in tourism 2007 proceedings of the international conference in Ljubljana, Slovenia, 2007</i> , Springer-Verlag, Vienna, pp. 12-32.
<i>For unpublished conference proceedings</i>	Surname, Initials (year), "Title of paper", paper presented at Name of Conference, date of conference, place of conference, available at: URL if freely available on the internet (accessed date). e.g. Aumueller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: http://dbs.uni-leipzig.de/file/aumueller05wiksar.pdf (accessed 20 February 2007).
<i>For working papers</i>	Surname, Initials (year), "Title of article", working paper [number if available], Institution or organization, Place of organization, date. e.g. Moizer, P. (2003), "How published academic research can inform policy decisions: the case of mandatory rotation of audit appointments", working paper, Leeds University Business School, University of Leeds, Leeds, 28 March.
<i>For encyclopedia entries</i>	<i>Title of Encyclopedia</i> (year) "Title of entry", volume, edition, Title of

<i>(with no author or editor)</i>	<p>Encyclopedia, Publisher, Place of publication, pages.</p> <p>e.g. <i>Encyclopaedia Britannica</i> (1926) "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia Britannica, London and New York, NY, pp. 765-71.</p> <p>(For authored entries please refer to book chapter guidelines above)</p>
<i>For newspaper articles (authored)</i>	<p>Surname, Initials (year), "Article title", <i>Newspaper</i>, date, pages.</p> <p>e.g. Smith, A. (2008), "Money for old rope", <i>Daily News</i>, 21 January, pp. 1, 3-4.</p>
<i>For newspaper articles (non-authored)</i>	<p><i>Newspaper</i> (year), "Article title", date, pages.</p> <p>e.g. <i>Daily News</i> (2008), "Small change", 2 February, p. 7.</p>
<i>For archival or other unpublished sources</i>	<p>Surname, Initials, (year), "Title of document", Unpublished Manuscript, collection name, inventory record, name of archive, location of archive.</p> <p>e.g. Litman, S. (1902), "Mechanism & Technique of Commerce", Unpublished Manuscript, Simon Litman Papers, Record series 9/5/29 Box 3, University of Illinois Archives, Urbana-Champaign, IL.</p>
<i>For electronic sources</i>	<p>If available online, the full URL should be supplied at the end of the reference, as well as a date that the resource was accessed.</p> <p>e.g. Castle, B. (2005), "Introduction to web services for remote portlets", available at: http://www-128.ibm.com/developerworks/library/ws-wsrp/ (accessed 12 November 2007).</p> <p>Standalone URLs, i.e. without an author or date, should be included either within parentheses within the main text, or preferably set as a note (roman numeral within square brackets within text followed by the full URL address at the end of the paper).</p>

8.1.1 Frequently asked questions

<i>Do you publish open access articles?</i>	For questions about open access, please visit the Open Access section of the website.
<i>Is there a submission fee for the journal?</i>	There are no submission fees for any of Emerald's journals.
<i>What should be included in my paper's word count?</i>	The word count for your paper should include the structured abstract, references, and all text in tables and figures. Each journal has a set word count parameter for papers – this information will be on the journal's homepage.
<i>How can I become a reviewer for a journal?</i>	Please contact the Editor for the journal, with a copy of your CV, to be considered as a reviewer.
<i>Who do I contact if I want to find out which</i>	Firstly, log in to your author centre on the journal's ScholarOne site, click on 'Manuscripts with Decisions' and check the 'status' column of the table that will

<p><i>volume and issue my accepted paper will publish in?</i></p>	<p>appear at the bottom of the page. If the Editor has assigned your paper to an issue, the volume and issue number will be displayed here. If this information is not present, then the Editor has not yet assigned your paper to a volume and issue. In this case you may email the Editor of the journal to ask which volume and issue your paper is most likely to feature in.</p>
<p><i>Who do I contact if I have a query about ScholarOne?</i></p>	<p>If you are having a problem on ScholarOne please email the journal's Editor or the Emerald Content Editor for help and advice.</p>
<p><i>Is my paper suitable for the journal?</i></p>	<p>If, after reading the journal's aims and scope (available in the 'about the journal' section of the website), you are still unsure whether your paper is suitable for the journal, please email the journal's Editor and include your paper's title and structured abstract. The journal Editor will be able to advise on the suitability of your paper.</p>
<p><i>How do I ensure anonymity of my manuscript for peer review?</i></p>	<p>you need to refer to your own work, please make sure that this is worded in such a way that you as author(s) cannot be identified e.g. "previous research has demonstrated" not "our previous research has demonstrated". Should the paper be accepted, you will need to contact the Editor to revise this ahead of publication you need to refer to your own work which is currently unpublished, then please do include this work in the reference list. Should the paper be accepted, you will need to contact the Editor to revise this ahead of publication any Acknowledgments or Author biographies should be uploaded as separate files where asked to 'Choose File Designation' choose the File Type, 'Acknowledgment' or 'Author Biographies', as appropriate please check the manuscript to ensure that the author names do not appear anywhere. This includes on Figures.</p>

Appendix J: Letters To Ethics Committees

Dear [REDACTED],

On the 29 July 2013 I attended a Research Ethics Committee chaired by you in respect of the study:

Study Title: **Developing an understanding of the impact of DBT on adults with a learning disability with emotion regulation difficulties.**

REC reference: 13/LO/1038

IRAS project ID: 103826

The Committee provided a provisional opinion and requested further information on five issues in order to confirm the opinion. The following is my response to the committee in this regard and I have included:

- A copy of the provisional opinion.
- A copy of the list of further information and clarification required.
- A brief description of the background history of the project.
- A response to each of the five issues.
- Copies of requested documents.

Provisional opinion:

1. The Committee raised concerns that the potential participants may feel pressure to enter the study as the cohort would be exclusively the patients of the yourself, the CI for the project. Discussion centred around the conflict between the possibility for coercion clouding the consent process and the reality of the small scale of the study necessitating this design . You accepted that coercion was a risk, but explained that, in his experience, patients would vote with their feet and just not turn up if they felt that they did not want to take part. The Committee was satisfied with this response.

2. The Committee also raised concerns regarding the PIS which was decided to be in need of re-writing in the standard NRES format as key points had not been addressed. You agreed to the Committee's request to re-write these in the standard question and answer format as well as creating 3 different, specifically tailored documents for carers, staff and patients.

3. The Committee was unsure of the focus groups as no topic guides had been provided. Though it was noted in discussion that specific questions would not be required, the topics being discussed were notable by their omission. You agreed to provide these as part of a written response.

4. The Committee was unsure of the details of the associate that had been referenced but not named in the study protocol. You explained that the previously unnamed [REDACTED] (sp.)

would assist him in the study and agreed to the Committee's request that the missing CV be submitted to as part of a written response. You also clarified that he would be conducting the therapy session.

5. The Committee raised concerns over the whether the study was student research and to what extent the IRAS submission had been correctly filled out. You explained that the study was a part doctorate piece of student research being funded by the University of Leicester and drew the Committee's attention to the named academic supervisor Steve Melliush. You also clarified that the study would represent only half of a final Doctorate. The Committee was happy to accept this explanation.

6. The Committee noted that little detail had been given in any explanation of those who lost the capacity to consent as well as those who became distressed. The Committee raised concerns that those who were adversely affected by the study would potentially be put back into the community without any support. You explained that with regard to distress caused during the study, the chances of this would be minimal given the participants having already been in this therapy for at least 6 months and up to 3 years.

7. The Committee raised specific concerns over disclosure of illegal or sensitive information, noting the lack of planning for this in the study documents. You assured the Committee that the law would be followed on this issue, but stipulated that the problem had not arisen in therapy so far and that the study participants would have between 6 months and 3 years of experience in this therapy group.

8. The Committee noted an irregularity surrounding the insurance in A76 of the IRAS submission. You confirmed that NHS indemnity through the site had been correctly stated and the University, though sponsor, was not responsible regarding endurance. You also confirmed that R & D had already confirmed their approval. The Committee was happy to accept this.

9. The Committee noted that the transcribing process as well as the length of time for which the data would be kept was not clear. You confirmed that he would transcribe the group discussions and dispose of the data when they had been written up.

Further information or clarification required

1. Drop down pages in IRAS to be filled out through a minimum data set process regarding student research. Advice to be sought from IRAS regarding this.
2. Clarification regarding insurance to be provided.
3. Topic guides for discussions to be submitted.
4. PIS to be rewritten in the NRES format forming 3 tailored, population specific documents.
5. CV to be submitted for previously unnamed associate.

Background Information

In October 2011 during my annual appraisal it was agreed by my service manager and professional lead that I should undertake a professional doctorate at Leicester University. A component of this doctorate is the requirement to undertake a research project. It was agreed that this project should have some benefit for the organisation and focus on the Dialectical Behaviour Therapy service for adults with a learning disability. The project was approved by my then Trust R&D lead and medical director [REDACTED]. On the 13th of September 2013 my service and I were TUPE transferred from [REDACTED]. As a consequence I have approached [REDACTED] R&D manager, [REDACTED] and this Trust has approved and agreed to sponsor my research.

My organisational contact is [REDACTED] service manager for [REDACTED]s adult learning disability service. He can be contacted at [REDACTED]
[REDACTED]

Response to point 1:

1. Drop down pages in IRAS to be filled out through a minimum data set process regarding student research.

I made an error in stating that the lead sponsor for the research was 'Academic' when answering the question A64.1 on the IRAS form and in providing contact details for my academic supervisor. This research is in fact sponsored by my NHS organisation [REDACTED] Trust'. Therefore this project is not student research for this purpose.

Response to point 2:

2. Clarification regarding insurance to be provided.

Correct completion of the field A64.1 would have supported my answer to question A76.1. The NHS indemnity scheme will apply. This can be confirmed by [REDACTED]
[REDACTED]

Response to point 3:

3. Topic guides for discussions to be submitted.

See appendix 1 for topic guides. This is version 1 of a new document and therefore no changes have been highlighted.

Response to point 4:

4. PIS to be rewritten in the NRES format forming 3 tailored, population specific documents.

See appendix 2, 3 &4 for revised PIS's. These three documents are derived from the single patient information sheet originally presented. Each incorporates a consent form for each group; therapists, carers and clients. Each from represents a new document identified as version 2 to differentiate them from the single document version 1 from which they were derived.

Response to point 5:

5. CV to be submitted for previously unnamed associate.

See appendix 5 for associate researchers CV. This is version 1 of a new document and therefore no changes have been highlighted.

I hope that this response meets with the committees requirements. If there are any points of clarity that require addressing during your consideration please contact me by mobile telephone

[REDACTED]

Sean Slater

Appendix K: Chronology of Research

Research Chronology:

Research commenced:	15th of January 2012
Ethical approval received. NRES NHS trust	8 th October 2013 15 th November 2013
Research carried out. Client focus Group: Carer focus group: Therapist focus group:	26 th of June 2014 02 nd July 2014 19 th February 2014
Research submitted:	13 th of January 2017