Dialectical Behaviour Therapy [DBT] with People with Intellectual Disabilities: A Systematic Review and Narrative Analysis

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Abstract

Background: There is mixed evidence regarding the effectiveness of psychological therapies for people with intellectual and developmental disorders. Although systematic reviews have supported the use of Dialectical Behaviour Therapy with people with Borderline Personality Disorder, there are no comparable reviews regarding DBT with people with ID/D.

Methods: Studies were identified using a systematic approach and were selected if they reported an intervention that included a DBT-skills group and then assessed using the Evaluative Method for Determining Evidence Based Practice

Results: Seven studies reported adaptations and outcomes of DBT for people with ID/D, four of which delivered full DBT programmes with three describing DBT-skills groups. All studies were appraised with regard to methodological quality and the adaptations and results examined.

Conclusions: The findings indicate that DBT and DBT-skills groups can be adapted for people with ID/D, but further high-quality research is needed in order to make conclusions about efficacy and effectiveness.

Introduction

Between 25-40% of people with intellectual and development disabilities (ID/D) in England have additional mental health needs (Giraud-Saunders, 2011). A review of personality disorder in people with ID/D concluded that it was not possible to estimate its prevalence due to findings ranging from 1-91% in community settings (Alexander & Cooray, 2003), but is likely to be higher than in the general population (Pridding & Procter, 2008). Recent UK government reports have highlighted the need for t improvements in adapting services to meet the needs of people with ID/D, who should have access to the same range of mental health services as the wider population (Department of Health, 2010; Prince et al., 2007).

There is mixed evidence regarding the adaptation of psychological therapies for individuals with ID/D. Brown et al. (2011) conducted a review of psychological therapies available to people with ID/D and

concluded that psychodynamic psychotherapy, cognitive-behavioural therapy (CBT), counselling and systemic family therapy can be adapted to be accessible for people with ID/D with positive outcomes reported, but many of the studies reviewed were small scale and of low methodological quality. More recent reviews of specific interventions have concluded that there is some evidence to support the use of psychodynamic therapies (James & Stacey, 2013), mindfulness-based interventions (Chapman et al., 2013; Hwang & Kearney, 2013) and CBT (Jennings & Hewitt, 2015; Nicoll et al., 2013) with people with ID/D. A recent meta-analysis of psychological therapies for people with ID/D by Vereenooghe and Langdon (2013) concluded that CBT was an effective treatment for anger and depression and that when CBT was excluded, adults with ID/D still benefited from psychological therapies, but there was insufficient evidence regarding the efficacy of psychological therapies for children and young people with ID/Ds. Systematic reviews of anger management with people with ID/D (Hamelin et al., 2013) interventions for offending behaviour with women with ID/D (Hellenbach et al., 2015) have indicated a lack of evidence for efficacy in both cases. Kok et al. (2015) concluded in their meta-analysis regarding psycho-social interventions for children with ID/D that there was an lack of good quality research.

Dialectical Behaviour Therapy [DBT] was initially developed by Linehan (1993a) ,who identified that individuals with parasuicidal behaviours tended to have poor outcomes after other forms of forms of treatment. The approach was then broadened for use with people with Borderline Personality Disorder [BPD] in the basis that self-injurious behaviour is associated with BPD (Linehan et al., 1991). DBT is an integrative treatment model that draws upon cognitive and behavioural approaches in addition to aspects of Eastern philosophy. It focuses on individual behavioural targets that are prioritised in a hierarchical order, namely life-interfering behaviours (self or others), therapy-interfering behaviours, DSM-IV Axis I disorders (American Psychiatric Association, 1994) and quality of life issues. Linehan (1993a) states that DBT treatment is multi-modal, consisting of individual therapy, groups skills training, telephone support and a staff consultation team. The groups skills training is outlined in Linehan (1993b) and includes four modules of emotional regulation, interpersonal effectiveness, distress tolerance and mindfulness. Individual sessions typically focus on client's recent behaviours and

work is supported through the use of diary cards. Recent incidents are reviewed using behavioural analyses and alternative solutions are identified. Telephone support is available on a 24-hour basis and is provided to support clients apply their coping skills in crises. Staff consultations are held in order to ensure that therapists remain motivated and provide effective treatment.

Initial randomised clinical trials compared DBT to treatment-as-usual and demonstrated that DBT led to reductions in frequency and severity of parasuicidal behaviours, reduced therapy attrition, reduced psychiatric admissions and improvements in measures of adjustment and anger for individuals with BPD (Linehan et al., 1993; Linehan et al., 1994). DBT has been recommended by the National Institute for Health and Clinical Excellence (2009) for the treatment of BPD, but also demonstrated to be effective for a range of difficulties including substance misuse (Linehan et al., 1999), trichotillomania (Keuthen et al., 2011), offending behaviours (Evershed et al., 2003; Safer et al., 2001; Telch et al., 2001), anger (Keuthen et al., 2011) and eating disorders (Rosenfeld et al., 2007; Sampl et al., 2010). It has also been successfully adapted for use with adolescents who self-harm, are 'oppositional defiant' or suicidal (James et al., 2008; Nelson-Gray et al., 2006; Rathus & Miller, 2002).

A Cochrane review found improved outcomes for DBT compared to standard care for self-harm, but concluded that further evidence was needed in order to make clear conclusions (Hawton et al., 1999). A further Cochrane review found that DBT improved outcomes on anger, parasuidality and mental health in BPD (Binks et al., 2006). A meta-analysis of DBT has shown that it is an effective treatment in reducing suicidal and self-injurious behaviours for individuals with BPD (Kliem, 2010). A recent systematic review of DBT skills training as a standalone treatment concluded that there was preliminary evidence for its applicability to a range of mental health problems, but the research evaluated was of poor quality which prevented strong conclusions being drawn (Valentine et al., 2015).

To date, there has not been a systematic review of the evidence regarding DBT for individuals with ID/D. Given the paucity of suitable evidence-based psychological therapies for people with ID/D, the present review systematically evaluated the available evidence regarding the use of DBT with people with ID/D.

Method

Search Strategy

The systematic review was conducted in accordance with the guidelines produced by The Centre for Reviews and Dissemination (2009). The following databases were searched in May 2015 for articles published in an English language journal from 1980-July 2013: AMED, EMBASE, HMIC, MEDLINE, PSYCINFO and PSYCARTICLES using the following search terms: (learning AND disab*) OR (mental* AND retard*) OR (intellectual* AND disab*) OR (developmental* AND disab*) AND (dialectical AND behav* AND therapy) OR DBT. The ancestry method was used to check the references listed in journal articles identified by the search and professionals or academics known to be interested in the field were also contacted to enquire whether they were aware of additional publications.

Selection Criteria

Studies were included if they (i) reported on interventions including DBT skills as a component, (ii) reported outcomes (quantitative or qualitative) relating to the DBT-based intervention described and (iii) included people with ID/D.

Search Results

After removal of duplicate papers, the search strategy identified 117 papers, 96 of which were subsequently excluded after reviewing the title and abstract and a further 14 were excluded following full review (Figure 1). A total of seven papers were included in the final systematic review.

[Figure 1 about here]

Quality Assessment, Critical Appraisal and Data Extraction

The quality of the seven studies was assessed using the *Evaluative Method for Determining Evidence Based Practice* (EMDEBP) (Reichow, 2011). This method was originally developed for use in reviews relating to Autistic Spectrum Disorders (ASD) and has been used for reviews of interventions for individuals with ID/D (Chapman et al., 2013). The methodology was selected as it is not limited to randomised controlled trials and can be used for research using small samples or for the evaluation of

single-case studies. The EMDEBP provides a rubric for evaluating group research consisting of both primary quality indicators (e.g. participant characteristics, presence of a comparison condition) on a trichotomous ordinal scale *(High, Acceptable* or *Weak quality*) and secondary quality indicators (e.g. random assignment, inter-observer agreement). The ratings from the primary and secondary quality indicators are combined to produce a strength of research rating (*Strong, Adequate* or *Weak*). Each study was independently evaluated by two members of the review team who then discussed each criterion until agreement was met.

Analysis

A narrative analysis, based on guidelines produced by the Centre for Reviews and Dissemination (2009), was used to describe and compare the main findings from each study and to delineate methodological strengths and limitations.

Results

Seven relevant studies were identified that used an adapted DBT programme based on the manual produced by Linehan (1993b). All studies presented quantitative findings and one study (Hall et al., 2013) also included a qualitative component. An overview of the studies is shown in Table 1 and a summary of the quality assessments using the EMDEBP is shown in Table 2.

1.1 Full Adapted DBT programmes for individuals with ID/D

Provision and adaptation of full DBT programmes for individuals with ID/D

Four studies used a full DBT programme (Linehan 1993a) consisting of DBT skills group, individual therapy, skills coaching outside of sessions and therapist consultation. One of the studies reported on DBT for adolescents with ID/D (Charlton & Dykstra, 2011), two studies reported on using DBT in community services (Brown et al., 2013; Lew et al., 2006) and a further study reported on using DBT in secure services (Morrissey & Ingamells, 2011). All bar one of the studies (Morrisey & Ingamells 2011) were from the USA.

Charlton and Dykstra (2011) reported the results of their DBT for Special Populations (DBT-SP) programme that was offered to all clients who attended a day centre for adolescents with 'developmental and behavioural needs'. Brown et al's. (2013) longitudinal study of the use of DBT with adults who had 'developmental disabilities' and a history of problem behaviours was the largest study to date on the use of DBT for people with ID/D, with all participants having received treatment at Justice Resource Institute-Integrated Clinical Services (ICS) after presenting with behaviours that challenged others and which had not improved in traditional mental health services. Lew et al. (2006) described their adapted DBT provided by a 'mental retardation' service for clients who presented with 'problem behaviours' in the community or were underserved by current services. Morrissey and Ingamells (2011) evaluated a pilot of an adapted DBT programme in a high secure ID/D service in the United Kingdom and referral criteria to the programme included meeting the diagnostic criteria for at least one personality disorder and difficulties due to a lack of emotional or behavioural regulation.

Within all the studies included within the review, the authors discussed the adaptations that have been made to their DBT programmes and all cited that they were based on the structure and content outlined by Linehan (1993a). Similarly, all of studies included group skills training based on the manual developed by Linehan (1993b) and the authors described adaptations, including the use of simplified language and concepts and increased visual aids to aid comprehension. Charlton and Dykstra (2011) discussed adapting the group skills training to increase the appeal of the content to adolescents. They also simplified some of the concepts to make them more suitable for adolescents with ID/D and provided increased feedback and rehearsal in order to increase learning and generalisation. Morrissey and Ingamell's (2011) adaptations primarily included simplification of language and the number of skills taught, repetition of concepts, increased creativity to promote engagement and understanding and increased used of visual images. The authors also discussed using smaller DBT programmes, with groups of 4-5 clients and an increased focus on individual workbooks and individual support with homework activities. Brown et al. (2013) described providing additional individual support with the group, whilst Lew et al. (2006) included staff or family members to support and coach participants.

All studies included weekly therapy, with Lew et al. (2006) using of twice-weekly 30 minute appointments and Charlton and Dykstra (2011) using twice-weekly group skills training of 30-60 minute duration compared to the weekly 90 minute sessions traditionally provided by DBT, with Charlton and Dykstra (2011) reviewing diary cards within these sessions, rather than in the skills training group.

Three studies (Brown et al., 2013; Lew et al., 2006; Morrissey & Ingamells, 2011) described how DBT self-monitoring procedures (diary cards) were adapted; with simplification of concepts and staff support in their completion, and Morrissey and Ingamells (2011) also used electronic notes to prompt the analysis of significant incidents.

All studies included having trained mental health professionals available on a 24-hour basis to provide coaching when clients were in crisis, but there were no specific adaptations for people with ID/D. In the interventions provided by community services, this coaching consisted of telephone support (Brown et al., 2013; Charlton & Dykstra, 2011; Lew et al., 2006). Morrissey and Ingamells (2011) did not provide 24-hour telephone support as DBT was delivered within an inpatient environment and staff with an awareness of DBT were general available for the participants.

All studies provided a therapist consulation but no specifc adaptations were reported. Morrissey and Ingamells (2011) stated that the consultation took place approximately every 4 to 6 weeks but did explain why this was so. Brown et al. (2013) also provided monthly skills system training to support staff and increased multidisciplinary input to promote skill generalisation.

The studies varied in the length of treatment provided. Brown et al. (2013) reported a mean treatment length of 82 months (6.9 years) and it is not reported whether any participants were considered suitable for therapy discharge during this period. The authors did not explain the rationale for the long treatment protocol, which was very long DBT is typically delivered for one-year in the general population (Linehan et al., 2006). Lew et al. (2006) delivered their weekly group skills training over 23 weeks and repeated this three times.

In addition to DBT, Charlton and Dykstra (2011) encouraged participants to engage with family therapy, although this was not a required part of the programme. Similarly Brown et al. (2013) provided clients with sexual offending histories with an additional hour per week of group offence-related work. They also described the use of additional behavioural treatment plans with participants including behavioural analysis of maladaptive behaviours and the use of tangible awards for adaptive behaviours.

Impact of full DBT programmes for individuals with ID/D

All four studies that provided a full DBT programme for individuals with ID/D provided it to different populations and had differing outcome measures. Brown et al. (2013) included all individuals who were receiving services at the ICS at the start of the research (n=40; 35 males, 5 females). Brown et al. (2013) reported that all participants had a diagnosis of 'developmental disabilities'. They reported the individual full-scale intellectual quotient (FSIQ) scores for all participants but not the assessment tool used to derive these scores. Eight participants (17.5%) did not have a FSIQ of less than 70 and their diagnoses included 'dementia-head trauma', 'attention-deficit/hyperactivity disorder', 'pervasive developmental disorder' and 'frontal lobe syndrome'. Two participants with a FSIQ greater than 79 had a 'not otherwise specified' diagnosis, and one participant (FSIQ=77) had 'paedophilia' as his only diagnosis. 95% of their participants had at least one Axis I disorder (American Psychiatric Association, 1994), and 60% of participants had a history of psychiatric hospitalisation with 70% having spent time in the two years prior in psychiatric hospital, residential treatment or locked forensic settings. 45% had forensic histories and all participants were reported to have a history of problem behaviours, defined as suicide attempts (18%), fire setting (23%), self-injury (48%), stealing (65%) or aggression (80%), and 67% of participants had a history of more than four problem behaviours.

Brown et al. (2013) measured outcomes using incident reports that were categorised on a trichotomous scale ('*red flags', 'dangerous situations'* and *'lapses'*), with the dependent variable being the number of problem behaviours in a month. The authors reported significant reductions in all categories of challenging behaviours after four years of treatment, with the greatest change occurring within the first year, however the authors noted that these descriptive statistics of incidents omitted missing data. Random regression modelling was used to include the potential impact of missing data on incident

reductions, and found that whilst the greatest reduction in lapses was within the first year, by the fourth year it had reduced by 76%. The authors explored which variables were most predictive of improvements in challenging behaviours. Although only small numbers were available, they found that the presence of borderline personality disorder (independent of self-injury or aggression) and aggression was predictive of larger reductions in lapses, with age being a predictor of aggression. Participants who had intermittent explosive disorder (IED) had significantly smaller reductions in lapses, indicating that DBT may be a less effective treatment for this group. The authors did not find a significant relationship between FSIQ and reduction in lapses. The authors did not include baseline data or a comparison condition; however they did report comparisons with baseline admissions to psychiatric hospital, residential treatment or locked forensic settings, with only two participants having admissions within the first two years of DBT, compared to 28 in the two years prior. Longitudinal outcomes are not reported further than four years, despite the mean length of treatment being considerably longer than this.

Lew et al. (2006) reported the outcomes of the first cohort of their DBT intervention which consisted of eight females, seven of whom had diagnoses of mild 'mental retardation', and one who had moderate 'mental retardation'. The mean number of Axis I disorders per participant was 1.38, and five participants had a diagnosis of personality disorder. Additionally, 50% had significant medical conditions. One participant chose not to attend group skills training, and instead received this on an individual basis. Lew et al. (2006) measured outcomes using an adapted version of the Youth Risk Behaviour Survey (RBS) (Centers for Disease Control and Prevention, 2001) in which they selected the 22 questions that they regarded as most relevant. Details of the questions selected or the psychometric properties of the RBS were not reported. The adapted RBS was completed at six monthly intervals by a team of 3-5 individuals in order to ensure agreement. Of the 22-items measured, it was reported that 54% of items had worsened from baseline within the first six months. By 12 months, there was improvement from baseline on 60% of items and this remained static at 18 months but at the 12 and 18 month assessment , scores for 18% of items has deteriorated. The authors suggested that the initial deterioration on the majority of items could be attributed to participants uncovering traumas prior to

developing skills to address these. Lew et al. (2006) reported that at the baseline six participants engaged in self-injurious behaviours and that this had decreased to two at 18 months but no further details about the domains of risk that improved or deteriorated were reported.

Morrissey and Ingamells (2011) reported that 25 clients had completed all four modules of the DBT skills group at least once with many also receiving additional individual therapy. They reported that no clients had dropped out of DBT but only reported the outcomes of six clients who received the full programme of DBT including group and individual therapy. It was not known whether these participants formed a representative sample of the population as no demographic data was reported and it was unclear as to whether any modules were repeated. Morrissey and Ingamells (2011) reported a significant reduction in individuals' scores on the Global Severity of Distress Scale of the BSI (Derogatis, 1993) following DBT. They did not find significant differences in incidents of aggression and attributed this to a low baseline level in high secure services. At a 12 month follow-up, their participants were more likely to have moved on to conditions of lower security than those on a waiting list control (n=5). It is unclear whether other outcome data was collected by the authors but not reported, for example, other indices of the BSI.

Charlton and Dykstra (2011) reported the outcomes of 19 students who completed two or more DBT-SP skills training modules. They reported that following DBT-SP clients were noted to be using 'DBT-SP language' and were observed to be using skills they had learnt, however, these aspects were reported anecdotally and were not quantified. The authors also reported the progression of sixteen students following DBT-SP, with ten having moved to less restrictive environments. However, the details of the restrictions in the evaluated service were not operationalised and a comparison was not available regarding the typical progression of students from the service. In addition, Charlton and Dykstra (2011) used information from daily diary cards as an outcome measure. They looked at the number of negative actions, thoughts and feelings that were self-reported by students, and reported significant negative correlations with months in the programme. The grouping of items of the diary cards did not discriminate the severity of outcomes, for example attempting suicide; arguing and avoiding work were all considered equally as action items. It was unclear whether the results were affected by being

calculated as cumulative months rather than individual days and the rationale for not using the daily scores was not made clear. This may have resulted in significant events, such as suicide attempts (an action item), being overlooked.

DBT skills groups for individuals with ID/D

Provision of DBT skills groups for individuals with ID/D

Three studies reported outcomes on adapted DBT skills groups; one within community services (Hall et al., 2013) and two within forensic secure services (Sakdalan & Collier, 2012; Sakdalan et al., 2010). The authors of all three papers stated that their programmes were based on Linehan (1993a). Sakdalan et al. (2010) and Sakdalan and Collier (2012) used the same group skills programme and reported that this was based on the coping skills programme for people with ID/D by Verhoeven (2007), but did not provide any further details. Hall et al. (2013) reported that handouts and diary sheets were adapted to use amended language and supplementary pictures to aid understanding of DBT skills, but further details of these adaptations were not included.

Hall et al. (2013) reported that a carers' component was included as a substitute for 24-hour support, however details of this are not discussed further. Sakdalan et al. (2010) described ongoing training and education to vocational and educational staff and the provision of additional support on completing DBT homework.

Hall et al. (2013) described the referral criteria for their DBT programme, namely that participants have an ID/D and present with difficulties related to emotional regulation, managing crisis, and interpersonal effectiveness. It was suggested that the group may be of value to those who present with impulsive behaviours including self-injurious behaviour and aggression.

The DBT skills group described by Sakdalan et al. (2010) and Sakdalan and Collier (2012) ran for 13-weeks, whilst Hall et al. (2013) did not report the length of their programme.

Hall et al. (2013) and Sakdalan et al. (2010) delivered their DBT skills groups as a standalone intervention, however Sakdalan and Collier (2012)'s intervention consisted of a seven-month pilot sex

offender treatment programme that incorporated a cognitive behavioural sex offender treatment programme for people with ID/D (SOTSEC-ID, 2010) with the DBT skills group training programme described in Sakdalan et al. (2010).

Impact of DBT skills groups for individuals with ID/D

Hall et al. (2013) conducted a mixed methodology study and measured outcomes of seven participants in the first cohort of their DBT programme but did not report attrition rates or any demographic information, such as gender or age. The authors found a decrease on measures of anxiety and depression and an increase in the use of mindfulness skills following treatment. The authors did not report any statistical analyses due to the small numbers and there were no measures directly related to risk or impulsive behaviours even though these formed part of the inclusion criteria for their study.

In addition to using formal measures, Hall et al. (2013) completed brief semi-structured interviews with five participants who attended the DBT group to explore whether individuals felt that the DBT programme helped them manage difficult emotions and situations. Using a thematic analysis, the authors identified four themes; '*good things about the group', 'bad things about the group', 'after the group'* and *'in the future'*. Overall the feedback was reported to be positive, with participants recommending it to others with similar difficulties, identifying positive changes in themselves including reduced self-harm or police involvement, finding the support of the group helpful and the material being presented in a format that was understandable. One participant commented that they found it difficult to retain information following the group and that they would have liked the group to continue for longer. Another participant found it difficult when other group members had sporadic attendance. Participants reported that they continued using the skills they had learnt in the group, particularly mindfulness and relaxation which was aided through the use of a CD. Suggestions for further improvements to the group included the opportunity for clients to attend two cohorts and the need for individual considerations regarding the length of the group.

Sakdalan et al. (2010) reported that nine participants started their DBT skills group, but only six (five males, one female) completed the programme. Participants were considered to have completed the

group if they attended at least 80% of sessions. All participants had a formal diagnosis of intellectual disability and the mean IQ of the group was 57 but the assessment tool used to measure this was not reported. Four participants were in 24-hour supported accommodation, and two were in medium secure facilities during their group attendance. The referral criteria to the group were not described, but it was reported that five participants had previous charges or convictions for violent behaviours. Sakdalan et al. (2010) reported significant improvements on risk and strength scores on the START (Webster et al., 2004) and global functioning as measured by the HoNOS-LD (Roy et al., 2002). They did not find significant improvements in coping skills as measured by the VABS-II (Sparrow et al., 2005). Data from incident reports were collected, but not reported as it was considered to be insufficient. A DBT assessment form was completed following the programme, however the details of this are not provided. The feedback provided by clients was reported as indicating that all participants enjoyed the group, but felt that further adaptations and support with material could be provided.

Sakdalan and Collier (2012) reported that five clients attended their sex offender treatment programme, three of whom consented to particapate in an outcome study. All three participants were male, with two being in their mid-30s and one in their mid-20s.. All three participants were placed in secure facilities for people with ID/D, had been convicted of sexual offences and were considered to be a high risk of sexual recidivism. Sakdalan and Collier (2012) present their outcomes in a multiple case series design and reported that all participants had improved scores on risk (SVR-20) (Boer et al., 2010), improvements in sexual knowledge (ASK) (Butler et al., 2003), victim empathy (VES) (Beckett et al., 1994) and cognitive distortions relating to sexual offending (SOSAS) (SOTSEC-ID, 2010) following treatment. Only one participant showed improvements on attitudes to sex offending (QACSO) (Lindsay et al., 2000). All participants had reductions in incident reports of sexually abusive behaviours in the six months following treatment, but two had an initial increase during treatment compared to the six months prior. One participant had reduced physical aggression following treatment, and one had reduced verbal aggression. All participants had increased reports of physical aggression during treatment, although it is of note that the baseline levels of physical and verbal aggression were low. It is not noted how incidents were coded.

Critical Appraisal

All of the studies were rated as *Weak* using the EMDBP (Reichow, 2011). Studies generally had small numbers of participants (mean N=13, range 3-40), resulting in poor external validity and limited generalisability of the findings. In addition to their limited size, studies varied in their recording of demographic information including gender, age and diagnoses leading to difficulties inferring for whom DBT would be most beneficial. Linehan (1993a) initially developed DBT primarily for females but in the studies that reported gender, only 17% of participants were female. This might have been influenced by the inclusion of studies undertaken in forensic services, where the population of males is considerably higher (Bartlett & Hassell, 2001). DBT is recommended for individuals with a diagnosis of Borderline Personality Disorder (Novaco & Taylor, 2004), however only one study (Brown et al., 2013) considered whether this was a contributory factor to the efficacy of DBT. Several of the studies did not define their referral criteria for their service or DBT, and this further contributed to the difficulties generalising the findings to a larger population. Related to this, the outcome measures used varied across studies and there was a lack of clarity regarding the goals of DBT. Several studies used incidents as an outcome measure, but previous research has found that staff consistently under-report incidents (Lion et al., 1981), in addition to potential bias by staff in categorising incidents. Reliability and validity of the measures used, and inter-rater reliability were not reported.

None of the studies provided sufficient information regarding adaptations of DBT for use with individuals with ID/D making it difficult to make conclusions about how effective these adaptations were or to replicate these. However, several studies did use manualised treatment (Charlton & Dykstra, 2011; Sakdalan & Collier, 2012; Sakdalan et al., 2010). Only one study (Brown et al., 2013) gave consideration to treatment fidelity, which was based on the evaluation of one session by DBT experts.

Several studies included additional therapies for some participants including family therapy (Charlton & Dykstra, 2011) and sex-offender treatment (Brown et al., 2013); Sakdalan and Collier (2012) integrated DBT group skills with sex offender treatment for all participants. None of the studies differentiated the outcomes of those participants who received additional therapies and it is unclear whether additional treatments had a confounding effect.

Only one study (Morrisey & Ingamells 2011) reported on a comparison condition in the form of a waiting list control group but it was not reported whether this was a comparable group either in terms of presenting difficulties and/or demographics. Two studies considered a period of baseline data (Sakdalan & Collier, 2012; Sakdalan et al., 2010). None of the studies gave consideration to the outcomes of participants who dropped out of DBT or who did not meet the criteria to have received sufficient DBT to be included; these participants could have potentially provided a comparison condition. The absence of comparisons makes it difficult to infer whether improvements are greater than would be expected spontaneously or through other available treatments. It is also unknown from the data whether any positive outcomes from DBT have a longstanding effect.

All the studies were evaluated by individuals involved in the provision of therapy, who also appeared to have collected most of the data and who were not therefore blind to the aims of the studies. Sakdalan et al. (2010) attempted to mitigate some of the effects of this by having pre-assessment measures completed by participants' key workers and not shared with the therapy team who completed the post-assessment measures.

Discussion

The studies identified by this systematic review indicate that the development of DBT services for people with ID/D is being considered internationally and across a range of settings. Common adaptations to DBT included the simplification of concepts and language, repetition of content, the use of visual aids and increased support for individuals in completing therapy materials. However, the available research did not provide sufficient information regarding the extent of the adaptations made that allow these to be replicated or the rationale and evidence for the stated adaptations. The published studies did not use robust designs, such as blinded allocation to groups, independent researchers or measures of adherence to treatment protocols and it is not possible to conclude that adapted DBT is an effective treatment for individuals with ID/D or that it was responsible for the various positive outcomes reported such as improvements on measures of risk, symptoms and challenging incidents. There is insufficient good quality evidence on to make judgements as to which groups of people with ID/D might

particularly benefit from DBT as there was insufficient information about the relationship of factors such as age, gender, ethnicity and diagnoses to the reported outcomes. Qualitative feedback within one study from people with ID/D suggested that they found it to be a suitable therapeutic approach, and that whilst adaptations had been made, further work could be done to ensure that it is accessible for people with ID/D. Consideration also needs to be given to whether DBT services are being accessed by people with ID/D in mainstream mental health services and whether these services are suitable. Future studies need to clearly define their referral criteria for DBT, and provide demographic information about participants.

The findings of the reviewed research should be considered with caution given the evident methodological weaknesses of all of the studies. As all of the research reviewed was rated as methodologically *Weak*, it is not possible to infer that there is emerging evidence for the efficacy of DBT for people with ID/D and better quality evidence is needed in order to conclude that DBT should be recommended for people with ID/D.

Whilst all studies based their interventions on the model of DBT initially outlined by Linehan (1993a), their adherence to the overall fidelity of the model varied, ranging from providing o DBT skills based group therapy to a multi-modal approach incorporating individual and group therapy, telephone support and staff consultation, whilst other some studies were based on interventions that included DBT as a component alongside offence-related work or family therapy. It is important that future researchers are more explicit about whether they are solely evaluating DBT or other interventions that result in change. In addition, recent systematic reviews have demonstrated that mindfulness is appropriate for people with ID/D (Chapman et al., 2013; Hwang & Kearney, 2013), and given that mindfulness is a component of DBT, it is important that future studies differentiate which components of the interventions are leading to change. None of the studies in the current review examined mechanism in DBT that are associated with positive outcomes, which is another area for future research.

Studies designed with appropriately powered sample sizes and random allocation to treatment and control groups are needed in order to infer whether DBT is responsible for improvements in symptoms

and incidents. Researchers should be independent of the therapy and blind to the allocation of participants. In addition, the DBT provided should more robustly adhere to the multi-modal approach developed by Linehan (1993a) without additional therapeutic approaches being used. Appropriate qualitative research could be used to compliment this work to understand the experiences of those who have delivered and received DBT and identify what components they believe are useful.

Due to the lack of consistency of interventions, populations and outcome measures in the papers identified in the current review, it is difficult to make meaningful comparisons and conclusions in the current review. Whilst a narrative synthesis can provide an initial scoping of the available evidence, if higher quality research were available it would be preferable to conduct a meta-analysis to quantitatively explore the impact of adapted DBT

Conclusion

In conclusion, there is evidence that services are attempting to provide adapted DBT for individuals with ID/D in a range of populations with the aim of demonstrating improvements on measures of well-being (symptoms of mental health, hospital admissions) and risk (risk assessment measures, incidents, conditions of security). However, there is an absence of methodologically sound research and it is not possible to make conclusions about the efficacy of adapted DBT for individuals with ID/D or recommendations for clinical practice.

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Table 1: Summary of studies evaluating DBT for people with ID/D

Study	Aims	Study type	Rigour	Sample	Intervention	Outcomes measured
Charlton and Dykstra (2011)	To discuss the adaptations made to DBT and their effectiveness for adolescents who have ID/D and mental illness	Multiple baseline design across participants	Weak	N=19 (gender not reported) Adolescent clients with significant developmental and behavioural needs in a day centre who were receiving DBT for special populations (DBT-SP)	• Group DBT skills training • Individual therapy • Crisis access, including after-hours emergency contact • Staff consultation	• Observational results • Progression following programme • Daily diary cards-action items, thoughts and feeling items
Brown et al. (2013)	To evaluate whether DBT with a skills system (DBT-SS) leads to a reduction in challenging behaviours amongst individuals with ID/D	Multiple baseline design across participants	Weak	N=40 (Males=35, Females=5) All received DBT-SS. All participants were diagnosed with 'developmental disabilities' with a mean IQ of 60.8. All had a history of severe problem behaviours.	• Group DBT skills training • Individual therapy • Skills coaching via telephone • Staff consultation	• Frequency and type of challenging behaviours in incident reports
Hall et al. (2013)	To evaluate a DBT group skills programme for adults with ID/D in a community setting	Mixed methods; Qualitative and Repeated measures design	Weak	N=7 (quantitative) N=5 (qualitative) Participants with an ID/D who were attending the psychological therapies services and were receiving adapted DBT. Highlighted that it would benefit those who exhibited impulsive behaviours including self-harm or aggression.	• Group DBT skills training • Carers' component as a substitute for telephone support	• Glasgow Depression Scale for People with a Learning Disability (GDS) (Cuthill et al., 2003) • Glasgow Anxiety Scale for People with an Intellectual Disability (GAS) (Mindham & Espie, 2003) • Cognitive and Affective Mindfulness Scale-Revised (CAMS-R) (Feldman et al., 2007)

Lew et al. (2006)	To evaluate whether DBT can be provided for individuals with ID/D	Repeated measures design	Weak	N=8 (Females aged 25-61) All received adapted DBT. 7 were diagnosed with 'mild mental retardation' and one was 'moderately retarded'. All presented with risks in the community and/ or were clinically underserved using current services. The average number of Axis 1 diagnoses was 1.38 per individual (38%=major depression, 25% schizoaffective disorder). 5/8 had diagnosed personality disorders.	• Group DBT skills training • Individual therapy • Coaching in crisis • Consultation team	• Adapted Youth Risk Behaviour Survey (RBS) (Centers for Disease Control and Prevention, 2001); 22 out of 87 items selected
Morrissey and Ingamells (2011)	To discuss the implementation of, and evaluate DBT within a High Secure ID/D service	Repeated measures design	Weak	N=6 All patients received adapted DBT within the National High Secure Learning Disability Service. All met diagnostic criteria for at least one personality disorder and had problems with lack of emotional or behavioural recognition.	• Group DBT skills training • Individual therapy • Telephone support not available, but therapists and DBT-aware support workers often available on wards • Therapist consultation- 4-6 weekly	Global Severity of Distress Scale of the Brief Symptoms Inventory (BSI) (Derogatis, 1993) Incidents of aggression Security level 12 months after treatment completion
Sakdalan et al. (2010)	To evaluate the effectiveness of an adapted DBT group skills training programme on offenders with ID/D	Repeated measures design No follow-up	Weak	N=6 All attended DBT group skills training programme. Males=5, Females= 1. Aged 23-29. All had prior charges and/or convictions for violent offences	• Group DBT skills training	Short-Term Assessment of Risk and Treatability (START) (Webster et al., 2004) Coping Skills subdomain of Vineland Adaptive Behaviour Scales-

	with a history of violent crimes			Forensic clients with ID/D (7=24hr supported accommodation, 2=medium secure facility).		Second Edition (VABS-II), (Sparrow et al., 2005) Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) (Roy et al., 2002) Incident reports (not reported) DBT assessment form
Sakdalan and Collier (2012)	To evaluate an adapted sex offender treatment programme which included an adapted DBT group skills training programme for individuals with ID/D	Multiple case study design	Weak	N= 3 All males, 1 in mid-20s, 2 in mid-30s. 2 lived in secure-ID facility and one lived in a community secure residential ID facility. All had committed sexual offences and were considered high risk of sexual recidivism. All completed SAFE-ID sex offender treatment programme and adapted DBT group skills programme	• Group DBT skills training • Adapted sex offender treatment programme	Adapted Sexual Violence Risk-20 (SVR-20) (Boer et al., 2010) Assessment of Sexual Knowledge (ASK) (Butler et al., 2003), Adapted Sex Offender Self-Appraisal Scale (SOSAS) (SOTSEC-ID, 2010) Questionnaire Attitudes Consistent with Sex Offending (QACSO) (Lindsay et al., 2000) Victim Empathy Scale (VES) (Beckett et al., 1994) Incident reports

Table 2: Quality assessments using the Evaluative Method for Determining EBP (Reichow, 2011)

Primary quality indicators	Charlton and Dykstra (2011)	Brown et al. (2013)	Hall et al. (2013)	Lew et al. (2006)	Morrissey and Ingamells (2011)	Sakdalan et al. (2010)	Sakdalan and Collier (2012)
***Participant characteristics* (*PART*)**	U	U	U	U	U	U	H

A high (H) quality rating is awarded to a study that meets the following criteria: 1. Age and gender are provided for all Participants (mean age is acceptable). 2. All participants' diagnoses are operationalized by including the specific diagnosis and diagnostic instrument (acceptable instruments include ADOS, ADI-R, CARS, DSM-IV, and ICD-10) used to make the diagnosis or an operational definition of behaviors and symptoms of the participants. 3. Information on the characteristics of the interventionist are provided (the ability to determine who did the intervention is minimal a criterion) and information on any secondary participants (e.g., peers) is provided. 4. If a study provides standardized test scores, the measures used to obtain those scores are indicated. An acceptable (A) quality rating is awarded to a study that meets criteria 1, 3 and 4. A study that does not meet all of criteria 1, 3, and 4 is of unacceptable quality and is awarded a U rating.							
***Independent variable* (*IV*) (e.g., *intervention*)** An H rating is awarded to a study that defines independent variables with replicable precision (i.e., one could reproduce the intervention given the description provided). If a manual is used, the study passes this criterion. An A rating is awarded to a study that defines many elements of the independent variable but omits specific details. A U rating is awarded to a study that does not sufficiently define the independent variables.	H	A	A	A	H	A	A
***Comparison condition* (*CC*)** An H rating is awarded to a study that defines the conditions for the comparison group with Replicable precision, including a description of any other interventions participants receive. An A rating is awarded to a study that vaguely describes the conditions for the comparison group; information on other interventions may not be reported. A U rating is awarded to a study that does not report the conditions for the comparison group or has no control or comparison group.	U	U	U	U	A	U	U
Dependent variable* (*DV*) *or outcome measure An H rating is awarded to a study that meets the following criteria: • The variables are defined with operational precision. • The details necessary to replicate the measures are provided. • The measures are linked to the dependent variables. • The measurement data is collected at appropriate times during the study for the analysis being conducted.	U	H	A	A	U	A	H

An A rating is awarded to a study that meets three of the four criteria. A U rating is awarded to a study that meets fewer criteria.							
***Link between research question and data analysis* (*LRQ*)** An H rating is awarded to a study in which data analysis is strongly linked to the research questions and uses correct units of measure (i.e., child level, teacher level, etc.) on all variables. An A rating is awarded to a study in which data analysis is poorly linked to the research questions but uses correct units for a majority of the outcome measures. A U rating is awarded to a study in which data analysis is linked weakly or not at all to the research questions and uses the correct unit for only a minority of the outcome measures.	H	H	A	H	A	H	H
***Statistical analysis* (*STAT*)** An H rating is awarded to a study in which proper statistical analyses were conducted with an adequate power and sample size (n > 10) for each statistical measure. An A rating is awarded to a study in which proper statistical analyses were conducted for at least 75% of the outcome measures or in which proper statistical analyses were conducted on 100% of outcome measures but with inadequate power or a small sample size. A U rating is awarded to a study in Which statistical analysis was not done correctly, the sample size was too small or the power was inadequate.	U	H	U	U	U	U	U
Total Strong= All H and ≥4secondary indicators Adequate= ≥4 H, 0 U and ≥2 secondary indicators Weak= <4 H and <2 secondary indicators	H=2 A=0 U=4	H=3 A=1 U=2	H=0 A=3 U=3	H=0 A=3 U=3	H=1 A=2 U=3	H=1 A=2 U=3	H=3 A=1 U=2
Classification	Weak	Weak	Weak	Weak	Weak	Weak	Weak

Secondary quality indicators **These indicators are rated on a dichotomous scale (there either is, or is not, evidence of the indicator).**	**Charlton and Dykstra (2011)**	**Brown et al. (2013)**	**Hall et al. (2013)**	**Lew et al. (2006)**	**Morrissey and Ingamells (2011)**	**Sakdalan et al. (2010)**	**Sakdalan and Collier (2012)**
***Random Assignment* (*RA*)** This indicator is positive if participants are assigned to groups using a random assignment procedure.	X	X	X	X	X	X	X
***Inter-observer Agreement* (*IOA*)** This indicator is positive if IOA is collected across all conditions, raters, and participants with reliability >.80 (Kappa >.60) or psychometric properties of standardized tests are reported and are >.70 agreement with a Kappa >.40.	X	X	X	X	X	X	X
***Blind Raters* (*BR*)** This indicator is positive if raters are blind to the treatment condition of the participants.	X	X	X	X	X	X	X
***Fidelity* (*FID*)** This indicator is positive if treatment or procedural fidelity is continuously assessed across participants, conditions, and implementers, and if applicable, has measurement statistics >.80.	X	X	X	X	X	X	X
***Attrition* (*ATR*)** This indicator is positive if articulation is comparable (does not differ between groups by more than 25%) across conditions and less than 30% at the final outcome measure.	X	X	X	√	√	X	X
***Generalization or Maintenance* (*G/M*)** This indicator is positive if outcome measures are collected after the final data collection to assess generalization or maintenance.	√	X	X	X	√	X	√
***Effect Size* (*ES*)** This indicator is positive if effect sizes are reported for at least 75% of the outcome measures and are >.40.	X	X	X	X	X	X	X
***Social Validity* (*SV*)** This indicator is positive if the study contains at least four of the following features: • Socially important DVs (i.e., society would value the changes in outcome of the study) • Time- and cost-effective intervention (i.e., the ends justify the means) • Comparisons between individuals with and without disabilities • A behavioral change that is large enough for practical value (i.e., it is clinically significant)	√	√	√	√	√	√	√

- Consumers who are satisfied with the results
- IV manipulation by people who typically come into contact with the participant
- A natural context