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INTELLECTUAL DISABILITIES (M FELDMAN AND R CONDILLAC, SECTION EDITORS)

Non-Behavioral and Non-Medical Psychosocial Interventions in Individuals with Intellectual Disabilities

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Abstract

Purpose of Review To review non-behavioral and non-medical psychosocial therapies for individuals with intellectual disabilities to identify if any such approaches are effective.

Recent Findings There are more randomized controlled trials (RCTs), systematic reviews, and meta-analyses than in the past; however, most RCTs are of poor quality.

Summary Most research treatments such as cognitive behavior therapy and diagnoses such as depression and anger. There is limited research on other forms of psychotherapy and other diagnoses. Future research needs to include high quality RCTs of psychosocial treatments for common, socially significant problems.

Keywords Intellectual disabilities · Psychological therapies · Depression · Anxiety · Cognitive behavior therapy · Systematic review

Introduction

There is a growing literature on psychosocial interventions in adults with intellectual disabilities (ID). This paper will review recent systematic reviews and meta-analyses of this literature and highlight directions for future research.

Cognitive Behavior Therapy

Cognitive behavior therapy (CBT) is a family of psychotherapy techniques based on the notion that changing the way people think and feel and the hypothetical underlying cognitive structures and processes results in behavior change. This can be achieved by various cognitive techniques such as identifying and modifying maladaptive thoughts and attributions and rationally evaluating the true likelihood of threats and dangers. CBT may address both cognitive deficits, such as a failure to generate and evaluate solutions to a problem, and cognitive distortions, such as believing one will die if one will go into a crowded store. CBT also includes conventional behavioral techniques, such as behavioral self-management, goal setting, self-recording, relaxation training, behavioral activation, graded exposure, and reinforcement from self, therapist, and others. More recent forms of CBT include so-called "third wave" behavioral interventions, such as acceptance and commitment therapy, DBT, and mindfulness. CBT is widely used in mental health treatment for a wide range of problems such as anxiety, depression, anger, violence and aggression, trauma-related conditions, addictions, and relationship problems. Reflecting the very large outcome literature for CBT and the frequent conclusion from government and professional bodies that CBT is an evidence-based practice, CBT is often regarded as the "industry standard" mental health treatment against which all other treatments must be judged.

Uptake of CBT with individuals with ID was slower than in other populations. This may have reflected a number of issues including a failure to recognize emotional disorders in this population, the predominance of behavior modification and behavior analytic treatments, the lack of psychometric instruments and interview

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protocols to diagnose and assess change in psychiatric symptoms and disorders, and the absence of basic research to justify CBT. The notion that therapeutic disdain for working with individuals with ID and that lack of CBT was a rights issue was also put forward as an explanation for the lack of uptake of CBT [1]. In the 1980s, the development of dual diagnosis as an intellectual and therapeutic movement addressed many of these issues [2–5]. Subsequently, there were publications of case studies and case series on various forms of CBT to address anxiety, depression, anger, and offending behavior, resulting in summary publications [6–8]. These publications focused on elementary questions such as whether and how CBT and other psychological therapies could be used with individuals with ID, how to modify standard forms of CBT, what prerequisite skills were needed to participate and benefit from CBT, how these skills could be taught, and what is the growing evidence base for these approaches to treatment.

Over the last 30 years, this literature has grown in size substantially, resulting in the publication of several systematic reviews and meta-analyses. Table 1 summarizes several broad narrative reviews and systematic review meta-analyses of CBT with individuals with ID. Table 1 shows that there is a growing literature on psychological treatments with narrative reviews predominating earlier and three of four meta-analyses being published more recently. These reviews and meta-analyses have reached widely varying conclusions ranging from psychotherapy being effective [10•], certain interventions such as parent training are moderately effective [17], certain forms of psychotherapy such as CBT being promising [13, 15••, 16••], the evidence for psychological therapies and challenging behavior is "thin" [14], and to the conclusion that there is no convincing evidence that both psychotherapy and psychotropic medication are effective [16••]. These very different conclusions reflect the use of different selection criteria for populations (such as degree of ID, age, type of mental health diagnoses addressed, whether the review addressed diagnoses or subclinical symptoms of a disorder, and inclusion or exclusion of autism spectrum disorders), treatment types, classifications of treatments, stringency of study quality inclusion, databases searched, and years searched. Thus, these meta-analyses sometimes analyze overlapping groups of papers and sometimes analyze very different literatures.

Some reviews have addressed specific populations. For example, Veerenooghe, Flynn et al. [18•] reported a systematic review of mental health treatment studies in children and adults with severe/profound ID. Unsurprisingly, they found a very small literature consisting of 2 small *N* experiments treating depressive symptoms and tics, 2 RTCs of imipramine for depressive symptoms and acting out pimozide for maladaptive behavior and hyperactivity, and one experiment evaluating haloperidol for tics. Few conclusions were made as the literature was small and of poor quality. Buijs, Bassett, and Boot [19] reported a systematic review of non-pharmacological treatment for individuals with 22q11.2 deletion, a rare genetic syndrome commonly associated with ID. They found only 5 treatment studies, including computerized software and social cognitive training to address social-emotional impairments and cognition. These two systematic reviews illustrate that when reviews focus on specific populations of individuals with ID, there are usually few studies available to review at this time.

Several papers have conducted systematic reviews and meta-analyses of psychological treatments for specific diagnoses. Table 2 summarizes these papers. The specific mental health problems addressed included CBT and other non-pharmacological treatments for depression, anxiety, mixed anxiety and depression, post-traumatic stress disorder (PTSD), and sleep disorders. Generally, treatments included CBT, behavior therapy, and sometimes psychotropic medication, such as melatonin for sleep disorders. Most papers commented on the small number of studies and their mixed and often poor quality resulting in difficulties in making strong conclusions related to treatment effectiveness or relative treatment effectiveness. Notable is the absence of reviews for some common mental health problems such as ADHD and psychosis.

Several studies have addressed the efficacy of specific forms of therapy with individuals with ID. The most commonly researched treatment has been anger management. There have been three meta-analyses of this approach (17–19] which, despite analyzing somewhat different studies and using different methods, have converges on the observation that the effect size for anger management is approximately 0.7–0.8 ("large"). For example, Vereenoogh and Langdon [13] meta-analyzed 9 studies (N = 494) and observed a SMD of 0.827 (CI 0.508, 1.146). Authors differed in their conclusions. Nicholl et al. [26•] concluded that anger management was effective whereas Hamelin et al. [27•] concluded that lack of treatment integrity data and other methodological limitations precluded that conclusion. Systematic reviews of dialectical behavior therapy (DBT) [28], psychoanalysis [29, 30], and psychomotor therapy (referring to progressive muscle relation and soles of the feet meditation) for anger and aggression [31] all revealed small literatures with poor quality studies for these approaches.

A final area of research has been into effective treatment in the context of forensic services for individuals with ID, including sexual offenders with ID. Table 3 summarizes these reviews. There is a moderate-sized literature on treatment of sexual offenders with ID and a

Table 1 A summary of broad systematic reviews and meta-analyses of psychosocial treatments with individuals with ID

Study	Type of review	Findings
Lindsay (1999) [9]	Narrative	Identified CBT treatment for 15 clients with anxiety, 5 with depression, 13 with anger management and 24 with sex offences.
Prout, & Nowak-Drabik (2003) [10•]	Systematic and meta-analysis	Searched the literature from 1968–1998 for papers on psychotherapy broadly defined, but excluding classroom-based behavioral studies. There were 92 studies including studies of group psychotherapy, play therapy, and counseling. A meta-analysis of 9 studies with control groups yielded a $d = 1.01$. The authors concluded that psychotherapy was moderately effective with individuals with ID.
Sturmey (2004) [11]	Narrative	Identified multiple studies of CBT on anger (including 2 RCTs), depression, and sex offenders, but noted few experimental evaluations, mis-labelling of behavioral techniques as cognitive techniques, and lack of conceptual and measurement clarity concerning the definition of treatment.
Willner (2005) [12]	Narrative	Identified evaluations of psychodynamic approaches (2 non-experimental studies), CBT approaches, such as self-monitoring, self-instruction, relaxation training, social problem solving, and 2 RCTS of anger management.
Vereenooghe, & Langon (2013) [13••].	Meta-analysis	Based on a systematic literature search on July 2012, 23 group experiments were entered into a meta-analysis. The overall effect size was moderate ($g = .6820$with randomized studies having a somewhat lower effect size ($g = -.555$) than non-randomized studies ($g = .846$). Individual therapy had a larger effect size than group therapy (g's = .778 and .558 respectively). Effect sizes varied by target problem (depression—$g = .742$, anger $g = .827$, interpersonal functioning $g = .342$.) The authors conclude that psychological therapy with individuals with ID was efficacious.
Campbell, Robertson, & Jahoda (2014) [14].	Systematic review	Searched the literature between 1980 and 2010 for psychological treatments for challenging behavior in adults with ID. Classified the evidence into a matrix format grading evidence as: A. > 1 meta-analysis, systematic review of high quality RCT; B. Well-conducted clinical studies without randomization; and C. Widely held expert opinion. There were 2 level A individual studies (functional analysis and behavioral interventions); 4 level B studies (problem solving, active support, PBS, and functional analysis); and 6 level C studies (5 function-based behavioral and 1 social problem solving). There were also 6 level A and 2 level C systematic reviews addressing function-based behavioral interventions, active support, positive behavior support and [10•] see above). The majority of the evidence supported function-based and positive behavioral interventions with less evidence for active treatment, but no mention of CBT, psychotherapy, or counseling, etc., in the matrix.)
Osugo & Cooper (2016) [15••]	Systematic	Used PRISMA procedures. Searched on 12/2014 for outcomes studies with adults with mild ID, any type of mental health issue, any psychosocial, pharmacological or ECT, with any quantitative data and a sample size > 20. Sixteen outcomes papers including 4 low-grade RCTs and 2 pilot studies. Most (7) treated depression or depressive symptoms but no studies addressed ADHD, dementia, or autism. Treatments were most commonly CBT (4 studies), exercise (2 studies), and behavioral activation (1 study); no RCTs addressed psychotropic medication or ECT. The authors concluded that the most promising treatments were CBT and exercise, but further studies are needed due to inclusion of subclinical populations and poor quality RCTs
Koslowski, et al. (2016) [16••]	Meta-Analysis	Using PRISMA procedures, they searched the literature published after 1980 in April 2013 and October 2014 for RCTs and controlled studies for adults with mild/moderate ID and mental illness or behavior problems. They identified 12 studies ($N = 724$), including 11 RCTs of which 10 were retained for meta-analysis. Studies addressed depression/depressive symptoms (3 studies), behavior problems (5 studies), biological treatments including psychotropic medications and multisensory treatments (3 studies), and system level interventions including assertive community treatment and case management (3 studies) and CBT (6 studies). There was little evidence of treatment effectiveness although the effect size for CBT (4 studies) approached significance ($d = 0.49$, $p = .08$). The authors concluded that there was a no evidence for the effectiveness of a wide range of treatments. This result was different than other reviews perhaps due to differences in sampling and power.
National Institute for Health and Care Excellence (2016) [17]	Systematic review of mental health studies	A systematic search for RCTs and controlled before-and-after studies identified (a) 3 RTCs and 1 other study for mixed mental health problems; (b)1 RCT on substance abuse; (c) 4 RCTs and 1 other study on anxiety; (d) 1 RCT on social anxiety; (e) 1 RCT on PTSD; (f) 4 RCTs and 3 other studies on depressive symptoms; and (g) 1

Table 1 (continued)

Study	Type of review	Findings
		other study on sexually inappropriate behavior. There were economic data from one feasibility study. All studies were of very low and low quality. The authors recommended considering CBT adapted for people with ID for depression and sub-threshold depression, relaxation, and graded exposure for anxiety.
National Institute for Health and Care Excellence (2016) [17]	Meta-Analysis of parent training studies	This meta-analysis expanded and updated the earlier meta-analysis from NICE [***] (2015) on parent training. NICE identified 15 RCTs (N = 819) with moderate effect sizes for behavioral and emotional problems (SMD = 0.4, moderate quality) and problem behavior (8 RCTs, N = 428, moderate quality, (RR = .67). Effect sizes for other outcomes (e. g., adaptive behavior) were smaller and involved low-quality studies. No studies addressed quality of life or community participation. No studies addressed staff training. There was some limited evidence of marginal economic benefits of intervention for group parent training under certain circumstances, but data were insufficient to explore all scenarios. The authors concluded that practitioners should consider CBT for depression and depression symptoms adapted for people with ID, relaxation training for anxiety symptoms, and graded exposure for anxiety symptoms or phobias.

Table 2 A summary of systematic reviews and meta-analyses of psychosocial treatments with individuals with ID for specific diagnoses

Study	Problem/type of review	Findings
Jennings & Hewitt (2015) [20]	Depression and CBT/systematic	Searched the literature from 1990 to 2014 and located 2 studies (1 case study, 1 RCT) of individual and 3 studies (2 pre-post group designs and 1 RCT of group CBT for depression. The studies provided "some support" for treatment of depression symptoms and mild depression
Hammers et al. (2018) [21•]	Depression and non-pharmacological treatment/systematic review	Used PRISMA guidelines to identify 15 studies of CBT (8 studies, of which 3 were controlled trials), behavior therapy (2 small N studies and 1 case series), exercise (2 RCTs), 1 study of problem solving (? 3 case studies), and 1 study of bright light therapy (3 case studies). Systematic Cochrane risk of bias tool was used to assess study quality which indicated that 2 studies had low risk of bias. The authors concluded that CBT was an effective treatment for depressive symptoms and mild depression in individuals with mild ID and that behavior therapy and exercise were promising treatments.
Dagnan et al. (2018) [22•]	CBT for anxiety in adults with ID/systematic review	Used Cochrane guidelines and searched the literature from 1940 to June 2017 to identify 19 articles with 107 participants, 75 with mild ID. Presenting problems included PTSD (3 studies), phobia (3 studies), obsessive compulsive disorder symptoms (9 studies), panic (1 study), hoarding (1 study), non-specific anxiety (7 studies), and 3 RCTs for mixed anxiety/depression. The most common treatments were psycho-education (9 studies), relaxation (13 studies), exposure (6 or 7 ? studies). There were 11 case studies, 1 used a small N design, 4 used group data 1 non-randomized and 2 randomized control trial.
Unwin et al. (2016) [23]	CBT for anxiety or depression/systematic	Searched the literature up to July 30, 2014 and identified 11 studies (N = 265): 3 for anxiety, 4 for depression, and 3 for mixed anxiety and depression. There were 3 RCTs. Study quality varied and all but 3 met minimal, liberal inclusion criteria.
Mevissen & de Jongh (2010) [24]	PTSD/systematic	Searched the literature from 1992 to 2008 and identified 9 non-experimental treatment studies. Treatments include interdisciplinary treatment, eliminating frightening cues, cognitive behavior therapy, exposure therapy, imagery rehearsal therapy for nightmares, and eye movement desensitization and reprocessing.
Shanahan et al. (2019) [25•]	Sleep disorders/systematic	Searched studies on sleep disorders in adults with ID from 1997 to 2017 using a Prospero registered search. They identified 9 studies of which 4 were for melatonin, 1 for functional assessment, 2 for mixed treatments, 1 for light therapy and 1 for imagery rehearsal. 7/9 studies reported improvements in sleep. Only 1/9 studies had low risk of bias. The high-quality study evaluated melatonin. The authors concluded that there was no evidence for clearly effective treatments for sleep disorders in adults.

Table 3. A summary of systematic reviews and meta-analyses of psychosocial treatments for sexual offending and related behavior with individuals with ID in forensic services

Study	Type of Review	Findings
Keeling et al. (2008) [32•]	Systematic	Searched the literature from 1996 to ? before 2008. The authors located 9 non-experimental studies of which 6 used CBT, problem solving, mixed CBT and behavior therapy and behavior therapy alone. Reoffence data reported in 8 studies varied from 0% to 4/14 (31%) over 6 months to 6.5 years (1 study did not state time period of follow up).
		The authors concluded that "some positive treatment change" (p. 142) occurred in all programs.
Ashman & Duggan (2008) [33]	Cochrane review	Failed to identify any RCTs. Recommended that practice be guided by research on sex offenders without ID and/or non-RCT data on sex offenders with ID.
Cohen & Harvey (2008) [34]	Systematic	Searched the literature ? from 2004 to 2008 and identified 10 non experimental studies of treatment of sexual offenders with ID. Some studies reported improvement in sexual knowledge, cognitions, victim empathy, coping, self-esteem, loneliness, and psychiatric symptoms. 8 studies reported an average recidivism was 7.8% (from 6 months to 5years).
		Study quality was not formally assessed, but problems included lack of treatment integrity data.
Marotta (2017) [35]	Systematic	Using PRISMA procedures, the author searched the literature from 1994 to 2014 and found 18 studies of which included 3 single treatment group designs, 6 multiple case studies with baselines, 1 multiple case study with no follow-up, and 3 quasi experimental designs; there were no RCTs. Treatments included CBT (13 studies), problem solving (1 study), DBT (1 study), mindfulness (1 study), and relapse prevention (1 study). Outcomes included cognitive changes and recidivism data.
		The author concluded the literature was very limited due to lack of experiments, treatment specification and integrity, and problems calculating recidivism.
Curtis et al. (2015) [36]	Systematic review	Searched the literature (years not stated) and found 4 studies of treatment of arson in individuals with ID. 3 were quasi experimental studies and 1 was a case study. Treatments included group-based education and CBT and multicomponent treatment packages including education, psychotherapy, and social skills. Studies reported reductions in fire setting following treatment.
		The authors concluded that due to the lack of experiments, treatment should be informed by the literature with arsonists without ID.

small literature on arson. There were no experimental studies on treatment of offenders with ID. Several authors recommended basing treatment considerations on the basis of treatment of offenders without ID.

Conclusion

There has been considerable activity in the areas of psychological therapy for mental health issues in adults with ID. This is shown by an increased number of treatment trials, including RCTs, more systematic reviews and meta-analyses, and systematic reviews and meta-analyses of specific diagnoses, especially depression and anxiety and anger and of specific treatments, especially CBT. The conclusions drawn have been quite disparate, even when reviewing largely the same outcome papers, with conclusions ranging from optimism, ambiguity, and pessimism regarding the effectiveness of psychological therapies. Generally, reviewers have commented on the poor quality of RCTs, with the exception of one or two RCTs. This literature is also difficult to interpret as each review answers different questions such as "Does CBT work?," "Does CBT work for depression," or "What works for depression?"

Future research should continue these efforts on three fronts. First, we need high quality RCTs to guide practice. Second, we need RCTs for common diagnoses which have not been addressed such as substance abuse, ADHD, and psychosis. Finally, it might be better if researchers and government bodies coordinated systematic reviews and databases in order to impose order on the search for evidence-based practice for mental health issues in adults with ID.

Compliance with Ethical Standards

Conflict of Interest Peter Sturmey received book royalties, speaker, and consultation fees related to this topic.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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