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Combining Clinical Interventions for Carers of People with Intellectual Disabilities

A systematic review of combined interventions for carers of people with developmental disabilities, and a realist evaluation of a combined acceptance and commitment therapy and positive behaviour support intervention for carers of children with intellectual disabilities

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Doctorate in Clinical Psychology

The University of Edinburgh

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Lay thesis summary

The first part of the thesis is a review of psychological interventions that are used to support carers of people with intellectual and developmental disabilities. People with intellectual and developmental disabilities can struggle with their thinking, moving and or socialising. Interventions that support carers of people with this kind of disabilities are often based on helping the carer understand the behaviour of the person they care for, and how best to cater to the person's needs (for example, interventions based on applied behaviour analysis). Other interventions, such as those based on mindfulness, or present moment awareness, are designed to help carers become less stressed by helping them adopt a different point of view on what it is that causes them to be stressed. In this review, we looked at interventions that combine both applied behaviour analysis and mindfulness, to find out if they work well at supporting carers. We then compared combined interventions with interventions based only on applied behaviour analysis, or only on mindfulness. Thirteen studies on the subject were found, with results showing that combined interventions are useful in reducing stress in carers, and in reducing challenging behaviour (that is, tantrums, aggressive behaviour, and similar) in people with an intellectual and or developmental disability. Results also indicated that combined interventions can be cheaper to implement in the long-term compared to interventions that only use applied behaviour analysis. More studies are needed that compare combined interventions with other interventions, including interventions that are based on mindfulness only.

The second part of the thesis looked at a combined intervention for carers of people with intellectual disabilities that had been recently trialled in Scotland, UK. This intervention blended together two psychological approaches: positive behaviour

support (PBS), which stems from applied behaviour analysis; and acceptance and commitment therapy (ACT), a type of therapy linked to mindfulness. Using an approach known as realist evaluation, we investigated how the combined intervention works, for whom it works, and what are the necessary circumstances for it to work. To do so, thirteen carers that took part in the intervention trial, and six experts in the fields of intellectual disabilities, PBS, and ACT were interviewed. At the interviews, carers were asked to share their experiences of the trial, while experts were invited to comment on the results of the trial, specifically, results that were unexpected. By analysing their responses, and comparing them against what is known about the two psychological approaches in question, we drew up a working model of the intervention. The model proposes that a combined PBS and ACT intervention likely works best when the two psychological approaches are truly combined, as opposed to being presented to carers separately. It also suggests that it is crucial to support carers in the regular practice of skills learned through the intervention by creating an environment that promotes the use of these skills. Finally, the model proposes that using a shared vocabulary should help carers be more open to practicing their skills, as well as promoting mutual support among carers. Future research should test this model, and study if the proposed modifications to the intervention can reduce carer stress and increase their wellbeing even more.

Prepared for Submission to the Journal of Applied Research in Developmental Disabilities

A systematic review of the effectiveness of combined Applied behaviour analysis-based and mindfulness-based interventions for carers of people with intellectual and developmental disabilities

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Abstract

Background: A systematic review was conducted to examine whether combined Applied behaviour analysis (ABA) and Mindfulness-based interventions (MBIs) are effective in increasing the psychological wellbeing and quality of life of carers of people with intellectual and developmental disabilities, and to determine whether combined interventions achieve more positive results than interventions delivered alone.

Methods: Using the Ovid search software, systematic searches of Ovid MEDLINE, APA PsychInfo, and Embase were conducted in November 2020. The review included studies that combined ABA and MBIs in interventions with both paid and unpaid carers, working and living in any setting, and caring for people of any ages.

Results: Thirteen studies involving 322 paid care staff and 195 parents of people with intellectual and developmental disabilities were included. Seven studies examined staff caring for adults, while the remaining six studies focussed on parents caring for their children (under 18 years old). Studies varied considerably in terms of design, sample size, diagnosis, and methodological quality. Within the context of these limitations, results tentatively suggest that combined ABA and MBI interventions are effective in decreasing carer stress and challenging behaviour, and that they can be more cost-effective than ABA interventions delivered alone.

Conclusion: While there is emerging evidence that combined ABA and MBI interventions are beneficial to carer wellbeing, it is not possible to draw firm conclusions on the basis of the existing literature. Future studies should aim at evaluating the effectiveness of combined interventions further using high quality randomized controlled trials.

Keywords: applied behaviour analysis, mindfulness based, developmental disabilities, intellectual disabilities, carers.

Introduction

Developmental disabilities is a broad term used to characterise people who vary from the norm in terms of their cognition, communication, social and or motor abilities (Odom et al., 2007). Such variations from the norm are developmental in the sense that they arise during the developmental stage of growing, a stage typically set between the ages of 0 and 22 years (Odom et al., 2007). Developmental disabilities encompass a wide range of disorders and impairments, some of which overlap with mental health diagnoses, such as intellectual disability, or autism spectrum disorder (ASD), while others do not, for example, cerebral palsy. For the purposes of the present review, developmental disabilities will be limited to those that are either cognitive, communicational, and or social in nature.

Despite the wide variation in presentation of developmental disabilities, and depending on the person's level of functioning, a common factor in this population is the need to be cared for, specifically, the need to be supported with cognitive, physical, and or social aspects of daily living. Carers can be both unpaid, such as parents, as well as paid, such as teachers or residential staff. Regardless of their relationship to the person they care for, carers often experience high levels of stress, as well as reduced psychological wellbeing as a function of their caring role (Emerson, 2003), factors which appear to be directly linked to the emotional, physical, and financial costs of caring for people with developmental disabilities (Herring et al., 2006; McIntyre, Blacher, & Baker, 2002). Carer stress appears to also be linked to stress in people with developmental disabilities, in what has been described as a bi-directional and self-reinforcing pattern (Hastings, 2002), whereby

stressed carers tend to increase the stress of those they care for, leading to an increase in challenging behaviours, which further increases carer stress.

Psychological interventions for carers of people with developmental disabilities

In light of the significant distress that often characterises carers, a multitude of psychological interventions aimed at reducing carer stress and at ameliorating the carers' psychological wellbeing have been developed. Among these, interventions which are based on, or which incorporate mindfulness principles at their core (Mindfulness-based interventions; MBIs) have recently flourished. MBIs are interventions rooted in the secular tradition of mindfulness, which is the practice of paying attention to the present moment, without judgement, and with qualities relating to a joyous acceptance of whatever is (Kabat-Zinn, 2003). As such, the aim of these therapies is to reduce the psychological impact of stress-inducing factors, such as challenging behaviour, and consequently increase the psychological wellbeing of its recipients. Despite a wide variation between existing interventions, the majority of the evidence base in this population stems from three such therapies, namely Mindfulness-based stress reduction (MBSR; Kabat-Zinn, 1990), Mindfulness-based cognitive therapy (MBCT; Teasdale, Segal, & Williams, 1995), and Acceptance and commitment therapy (ACT; Hayes, Strosahl, & Wilson, 1999).

The use of MBIs in carers of people with developmental disabilities has demonstrated promising results, albeit with some discrepancies (Rayan & Ahmad, 2018). Such discrepancies have been hypothesised to derive from differences in treatment length, with a trend suggesting that the shorter the treatment, the smaller the decrease in carer stress, with particularly short interventions having been

observed to bear no difference to carer stress levels compared to waiting list conditions (Ó Donnchadha, 2018). Moreover, at least one study noted an increase in carer stress between the end of the intervention and follow-up (McConachie, McKenzie, Morris, & Walley, 2014), although carer stress at follow-up remained significantly below baseline levels. This result may appear paradoxical; however, mindfulness-based practices are designed to fundamentally alter a person's relationship with their subjective experiences (Shapiro, Siegel, & Neff, 2018), which can lead to an initial increase in stress, before plateauing, and only subsequently resulting in decreased stress. Conversely, the majority of methodologically strong studies relating to the use of MBIs in carers of people with developmental disabilities suggest that reductions in psychological distress in carers are maintained for at least 6 months following the end of the intervention (Ó Donnchadha, 2018). This result appears to be again moderated by the length of the intervention, as well as by the use of post-intervention refresher sessions. Furthermore, there is some evidence that longer interventions which include refresher sessions tend to obtain the best results (Ó Donnchadha, 2018). Such indications however remain of preliminary value, given the scarcity of large-scale, randomised trials in the field, and in light of the complex mechanisms of mindfulness-mediated psychological changes.

Psychological interventions for people with developmental disabilities

Parallel to the above, are psychological interventions designed to help make sense of, and subsequently manage stress-inducing factors such as challenging behaviours. These interventions derive their frameworks from long-established behavioural models, most notably Applied behaviour analysis (ABA; Remington, 1998), and are currently widely used in both residential and community settings. A

prominent example of such interventions is Positive behaviour support (PBS; Gore et al., 2013), a person-centred, systemic intervention which is considered to be the best practice approach in the UK for people with developmental disabilities who display challenging behaviour (British Psychological Society, Division of Clinical Psychology, 2018). Evaluating the effectiveness of behavioural interventions for the management of challenging behaviours is a complex endeavour, as factors linked to treatment efficacy range from reductions in the frequency of challenging behaviours, to increases in the quality of life of carers, to that of the people being cared for, to name a few. To illustrate this complexity, a recent review on the use of PBS with people with developmental disabilities highlighted that carers trained in PBS gained an increased understanding of challenging behaviour, and noted a reduction of such behaviours when PBS was implemented consistently (MacDonald & McGill, 2013). Conversely, Dench (2005) reported no positive changes to the lifestyle of people with developmental disabilities, such as increased earning potential or having better social interactions following the implementation of PBS strategies in a large Irish sample, in spite of a reduction in the frequency of challenging behaviour observed. Naturally, it could be argued that the frequency of challenging behaviour does not correlate with indices of positive social interactions and employability; nonetheless, studies in this field tend to measure the efficacy of interventions on the basis of what are potentially unrelated indices. Finally, it is not uncommon for studies to dispute the sensitivity of the outcome measures employed (e.g., Corti et al., 2018), which further complicates the reliability of outcome-based research in this population.

Despite the mounting evidence on the effectiveness and efficacy of each of these two strands of psychological interventions, namely those aimed at people who are

being cared for, such as PBS, and those aimed at their carers, such as ACT, a comprehensive review evaluating the efficacy of interventions which combine elements of both is yet to be undertaken. Given that MBIs aim to affect changes in how one relates to their experiences, such combined interventions have the potential to significantly increase the efficacy of ABA-based interventions by virtue of changing one's approach to the intervention, while simultaneously addressing the psychological wellbeing of both carers and those who are cared for. The present review therefore aims to answer the following questions:

1 Are interventions which combine Applied behaviour analysis (ABA)-based interventions with Mindfulness-based interventions (MBIs) effective in ameliorating the psychological wellbeing and quality of life of family members and carers working with people with developmental disabilities?

2 Are interventions which combine ABA-based interventions with MBIs more effective, within the same parameters, than ABA-based or MBI-based interventions alone?

Methods

The systematic review was registered prospectively on Prospero (ID number: CRD42020222399), an international database of systematic reviews. Following registration, the Preferred reporting items for systematic reviews and meta-analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009) framework was employed to guide the review's search strategy.

Search strategy

Using the Ovid search software, the following databases were searched systematically: Ovid MEDLINE, APA PsychInfo, and Embase. The time brackets for the search ranged from the start of each of the databases' records, to when the search was undertaken (second week of November 2020). The search terms employed were (*variable of interest in brackets*): mindfulness; mindful; applied behaviour analysis; positive behaviour support (*interventions*); developmental disabilities; learning disabilities; autism (*clinical presentations/diagnoses*); parent; mother; father; carer; staff; support (*carer type*). The search terms were cross-referenced by an experienced librarian at NHS Grampian.

In the first stage of the review, retrieved studies were scrutinised by title; studies that clearly did not match the eligibility criteria as listed below were excluded. In the second stage, study abstracts were screened for relevance. Finally, in the third stage, full-text studies were reviewed in full.

The inclusion criteria were based on PICOS (Participants, Interventions, Comparators, Outcomes, Study design) systematic review protocol (Centre for

review and dissemination; 2009). Studies were included if they met all of the following criteria:

- **Participants:** studies of participants who are family members or paid professionals working with people with developmental disabilities. Family members are defined as individuals united by blood or by marital, adoptive, or other intimate ties.
- **Interventions:** Any intervention which combines applied behaviour analysis (ABA)-based intervention(s) with mindfulness-based intervention(s) (MBI). ABA-based interventions are defined as interventions that use strategies based on the principles of behaviour to improve socially significant behaviours (Cooper, Heron & Heward, 2019). MBIs are defined as any intervention that includes the practice of directing one's attention on the present moment, on purpose, and without judging (Kabat-Zinn, 2003).
- **Comparators:** As it is not anticipated that many studies with between-group comparators will be available, the review will include any within-group or between-group comparators. The secondary review question ("Are interventions which combine ABA-based interventions with MBIs more effective, within the same parameters, than ABA-based or MBI-based interventions alone?") will be addressed by reviewing studies that employed either ABA-based or MBI interventions as between-group comparators.
- **Outcomes:** Any outcome related to the psychological wellbeing or quality of life of family members or paid carers working with people with developmental disabilities. Psychological wellbeing is defined as wellbeing relative to individual and social life, including (but not limited) to stress, happiness, and

interpersonal effectiveness. Quality of life is similarly defined as the degree to which an individual is comfortable and able to participate in or enjoy life events, for example, work and family life.

Studies were excluded from the review if they met either of the following exclusion criteria:

- Redundant reports (in cases where there are multiple studies using the same data, the most recent study with the largest sample size will be used).
- Qualitative studies. This is due to the present review focussing on outcome measures that allow for a quantitative evaluation of the efficacy of the interventions of interest.

Data extraction

A data extraction table was used to code relevant variables and extract data, namely: Study Design, Setting, and Country; Participants; Sample size; Gender, Mean age; Type of intervention; Diagnoses of clients/dependants; Outcome measures; and Relevant findings.

Quality assessment

A quality assessment of included studies was undertaken for the purposes of the review. Due to the methodological heterogeneity of the included studies, a quality assessment checklist devised for both randomised controlled trials (RCTs) and non-RCT health care interventions was selected (Downs & Black, 1998). The checklist was found to have high internal consistency, good test-retest and inter-rater reliability, and good face and criterion validity by its authors (Downs & Black, 1998). The checklist includes 27 questions, which assess the quality of studies' reporting,

external validity, internal validity, and power. In terms of quality assessment, it is important to distinguish between quality of reporting, and quality of method (external validity, internal validity, and power), as the former is not related to the quality of evidence, merely its presentation. As such, the total quality of reporting and quality of method scores are presented separately.

Each question on the checklist received an answer of “yes”, “no”, “not recorded (NR)”, “not applicable (NA)”, or “could not determine (CD)”. A “yes” answer received a score of 1, while all other answers received a score of 0. In addition, question 5 of the assessment checklist includes a “partially (P)” answer, which receives a score of 1; a “yes” answer on this question received a score of 2, while a “no” answer received a score of 0. Previous research has recommended a cut-off point of 14 to differentiate between high- and low-quality studies, (Livingston, Milne, Fang, & Amari, 2012), that is, studies which obtained half or more points of the maximum total of 28 were given a high-quality rating. As the present review distinguishes between quality of reporting and quality of method, the same distinction between high- vs low-quality was applied to the quality of method total score: studies scoring half or more points of the maximum total of 18 (i.e., 9 points or above) were rated as being of high quality.

Following the quality assessment of the first author; a second reviewer assessed the quality of 50% of included studies, selected at random using a random number generator, to minimise quality assessment bias. The concordance between first and second reviews was high, with reviewers assessing 100% of the papers as either low- or high-quality. Overall, six papers were assessed as being of low methodological quality (Pess, 2016; Raulston et al., 2019; Singh et al., 2006, 2014a, 2014b; Singh, Lancioni, Karazsia, Chan, & Winton, 2016b).

Results

Search results

An initial database search yielded 173 results; two additional studies were included following a personal communication with colleagues, including an unpublished doctoral thesis. Following removal of duplicates, 135 abstracts were screened for inclusion criteria, and 108 studies excluded. 27 studies were then assessed in their entirety for eligibility, with a further 15 studies excluded on the basis of either: having an unsuitable study design (N = 1); using an unsuitable intervention (N = 12); or due to being conference abstracts (N = 2), leaving a final total of 13 studies included in the present qualitative synthesis.

Please refer to Table 1 for a summary of the main characteristics of the included studies.



PRISMA 2009 Flow Diagram

Search ran 20/11/2020

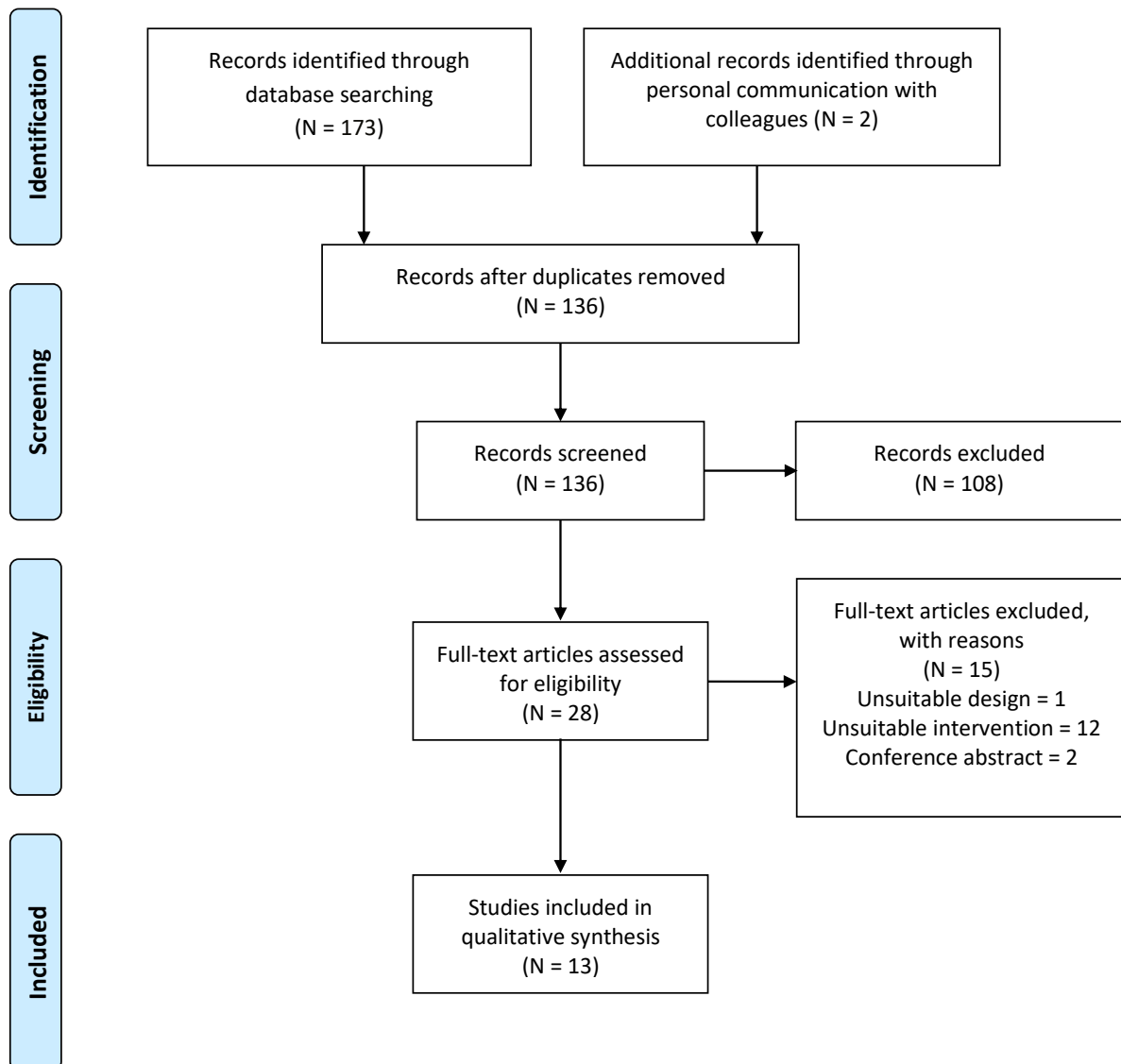


Figure 1. PRISMA flow diagram.

Characteristics

Table 1. Characteristics of included studies

Authors (Year)	Study Design; Setting; Country	Participants	Sample size (Intervention; Control)	Gender; Mean age	Intervention (Control)	Diagnosis of clients/ dependants (Children/ Adults)	Outcome measure(s)	Relevant findings
Bethay et al. (2013)	Controlled pre-post; Residential; USA	Staff	34 (18; 16)	76.5% ; 38 years	ACT + ABA (ABA)	ID (Adults)	GHQ-12; MBI; BBS; SVS	Participants with pronounced psychological distress at pre-test exhibited a significantly greater reduction in psychological distress when exposed to the ACT + ABA group as compared to ABA only ($p = 0.12$). No other between-group differences observed.
Connolly (2020)	Multiple baseline single-case; Community; UK	Staff and Parents	37	70% female; 43 years	ACT + PBS	ID (Children)	DASS-21; CBSES; CBI; CompACT; WEM	Significant decrease in psychological distress ($p = 0.002$), and significant increase in psychological flexibility ($p = 0.002$).
Corti et al. (2018)	Controlled pre-post; Community; Italy	Parents	42 (20; 22)	52% female; 39 years	ACT-PT + EIBI (EIBI)	ASD (Children)	PSI-SF; MAAS; CFQ	A trend towards significant decrease in stress in the ACT-PT + EIBI group ($p = 0.06$).
Pess (2016)	Single-case acceptability study; Community; USA	Parents	9	89% female; NR	Alternating ACT and BBI	ASD and PDD-NOS (Children)	PSI-SF; AAQ-II; PAAQ; SAQ; PASQ	The intervention was found to be acceptable and useful. Measures of psychological distress not employed in present study.

Authors (Year)	Study Design; Setting; Country	Participants	Sample size (Intervention; Control)	Gender; Mean age	Intervention (Control)	Diagnosis of clients/ dependents (Children/ Adults)	Outcome measure(s)	Relevant findings
Raulston et al. (2019)	Multiple baseline single-case; Community: USA	Parents	3	100% female; 33 years	MBI + PT	ASD (Children)	BMPS; SUDS; 10-s partial interval recording of CB	Medium effect for increases in behavioural strategy use ($g = 1.02$). Small to moderate decrease in parental stress ($g = 0.32$) and child CB ($g = 0.24$).
Singh et al. (2006)	Multiple baseline single-case; Residential; USA	Staff	15	33% female; 30 years	Behaviour training followed by mindfulness training	Severe to profound DD (Adults)	Frequency of target behaviours (i.e., staff interventions for aggressive behaviours); Staff work satisfaction.	Target behaviour frequency did not decrease following behaviour training, but did decrease following mindfulness training. Staff was most satisfied with their work following mindfulness training.
Singh et al. (2014a)	Multiple baseline single-case; Community: USA	Parents	3	100% female; 40 years	MBPBS	ASD (Children)	PSS-10	Significant decrease in episodes of child aggressive incidents ($p < 0.001$) and disruptive behaviours ($p < 0.001$). Significant reduction in parental stress ($P < 0.01$).
Singh et al. (2014b)	Multiple baseline single-case; Residential; USA	Staff	9	67% female; 42 years	MBPBS	DD (Adults)	Frequency of target behaviours (i.e., verbal redirections, physical restraints, staff injuries, peer injuries); PSS-10; Cost-effectiveness	All target behaviours frequency significantly decreased following intervention, as well as staff stress ($p < 0.001$). 87.75% reduction in financial burden to care provider following intervention.

Authors (Year)	Study Design; Setting; Country	Participants	Sample size (Intervention; Control)	Gender; Mean age	Intervention (Control)	Diagnosis of clients/ dependents (Children/ Adults)	Outcome measure(s)	Relevant findings
Singh et al. (2016a)	Single-case pre-post; Residential; USA	Staff	33	48% female; NR	MBPBS	IDD (Adults)	Frequency of target behaviours (i.e., physical restraints; staff injuries; peer injuries); PSS-10; Cost-effectiveness	All target behaviours frequency significantly decreased following intervention, as well as staff stress ($p < 0.001$). 89.27% reduction in financial burden to care provider following intervention.
Singh et al. (2016b)	RCT; Residential; USA	Staff	75 (37; 38)	63% female; 44 years	MBPBS (ABA – training as usual)	IDD (Adults)	Frequency of target behaviours (i.e., physical restraints; aggressive events; emergency medication; 1:1 staffing); PSS-10; Cost-effectiveness	MBPBS was significantly more effective in reducing frequency of physical restraints and emergency medication compared to ABA. Staff stress was also significantly better managed in the MBPBS group. Cost-effectiveness indicate a 78% reduction in financial burden to care provider during implementation of MBPBS.
Singh et al. (2018)	RCT; Residential; USA	Staff	166 (59; 57)	70% female; 43 years	MBPBS (PBS)	IDD (Adults)	Frequency of target behaviours (i.e., physical restraints; staff injuries; peer injuries; aggressive events; emergency medication; 1:1 staffing); PSS-10; ProQOL; Cost-effectiveness	MBPBS was uniformly significantly superior as compared to PBS (all results at $p < 0.001$). Cost-effectiveness analysis revealed a 0.5 million USD cost savings to care provider when implementing MBPBS as compared to PBS.

Authors (Year)	Study Design; Setting; Country	Participants	Sample size (Intervention; Control)	Gender; Mean age	Intervention (Control)	Diagnosis of clients/ dependents (Children/ Adults)	Outcome measure(s)	Relevant findings
Singh et al. (2019)	Multiple baseline between-group (ASD and ID); Community; USA	Parents	92 (47; 45)	100% female; 48 years	MBPBS	ASD or ID (Children)	Frequency of target behaviours (i.e., aggressive behaviour, disruptive behaviour, compliance with mother's request); PSS-10.	Both ASD and ID groups reported a decrease in stress, with mothers in the ID group reporting significantly higher stress at baseline. All target frequency behaviours of both ASD and ID groups significantly decreased following intervention ($p < 0.001$).
Weitlauf et al. (2020)	RCT; Community; USA	Parents	46 (24; 22)	83% female; 33 years	P-ESDM + MBSR (P-ESDM)	ASD (children)	PSI-SF; CESDS; BAI; SWLS; FFMQ	Both groups significantly improved in terms of parental stress ($P < 0.001$), with P-ESDM + MBSR group showing significantly greater improvement compared to P-ESDM. No between-group differences in depressive symptoms, anxiety, and life satisfaction at post-intervention (all significantly improved, $p < 0.05$).

Abbreviations:

NR: not reported
RCT: Randomised Controlled Trial

Diagnoses

DD: Developmental Disabilities
ID: Intellectual Disabilities
IDD: Intellectual and Developmental Disabilities
PDD-NOS: Pervasive Developmental Disability – Not Otherwise Specified
ASD: Autism Spectrum Disorder

Interventions

ACT: Acceptance and Commitment Therapy
ACT-PT: Acceptance and Commitment Therapy-oriented Parent Training
ABA: Applied Behaviour Analysis
PBS: Positive Behaviour Support
EIBI: Early Intensive Behavioural Intervention
BBI: Behaviourally-Based Intervention
bMBI: brief Mindfulness Based Intervention
PT: Parenting Training
MBPBS: Mindfulness-Based Positive Behaviour Support
P-ESDM: Parent-implemented-Early Start Denver Model

MBSR: Mindfulness-Based Stress Reduction

Outcome measures:

AAQ-II: Acceptance and Action Questionnaire-II
PAAQ: Parental Avoidance and Action Questionnaire
SAQ: Session Acceptability Questionnaire
DASS-21: Depression and Anxiety Scale – 21
CBSES: Challenging Behaviour Self-Efficacy Scale
CBI: Copenhagen Burnout Inventory
CompACT: Comprehensive Assessment of ACT Processes
WEM: Workshop Evaluation Measure
PASQ: Program Acceptability and Satisfaction Questionnaire
PSS-10: Perceived Stress Scale – 10
ProQOL: Professional Quality Of Life
CESDS: Center for Epidemiologic Studies Depression Scale
BAI: Beck Anxiety Inventory
SWLS: Satisfaction With Life Scale
FFMQ: Five Facet Mindfulness Questionnaire
PSI-SF: Parenting Stress Index – Short Form
MAAS: Mindfulness Attention and Awareness Scale
CFQ: Cognitive Fusion Questionnaire
GHQ-12: General Health Questionnaire-12
MBI: Maslach Burnout Inventory
BBS: Burnout Believability Scale
SVS: Social Validity Survey
BMPS: Bangor Mindful Parenting Scale
SUDS: Subjective Units of Distress Scale

Paid carers characteristics

Six studies focused on paid carers, for a total of 322 participants across all studies. All paid carers were staff working in residential settings in the USA. A slight majority of staff were females (N = 216; 65%), with mean ages ranging between 30 and 44 years. One study (Singh et al., 2016a) did not report the ages of carers. All six studies looked at carers working with adults with developmental disabilities.

Unpaid carers characteristics

All unpaid carers included in the reviewed studies were parents, for a total of 195 parents across all studies. With the exception of Corti et al.'s (2018) study which looked at parents living in Italy (N = 42), and of Connolly's (2020) study which was based in the UK, all other parents were recruited in the USA. All seven studies recruited parents from community settings. A significant majority of participants were mothers (N = 166; 85%), a fairly common imbalance in studies of parents of people with developmental disabilities. The mean ages of parents were between 33 and 48 years, with one study not reporting on this figure (Pess, 2016). All dependants were children below the age of 18.

In view of the clear demarcation in the reviewed studies between paid carers that worked with adults with developmental disabilities, and parents that cared for children with developmental disabilities below the age of 18, dependant characteristics will be summarised according to this divide.

Characteristics of adults with developmental disabilities

The study by Bethay et al. (2013) focused on adults with a diagnosis of intellectual disability, while the study by Singh et al. (2006) was based on carers working with adults with diagnoses of developmental disabilities ranging from severe to profound. The remaining four studies focused on carers working with adults with either developmental, or intellectual disabilities only.

Characteristics of children with developmental disabilities

All seven studies employed a sample of children with a diagnosis of autism spectrum disorder (ASD). In addition, Pess et al. (2016) also looked at children with pervasive developmental disorders not otherwise specified, while Singh et al. (2019) included children with either ASD or intellectual disabilities in their sample.

Methodology

Four studies that were based on smaller sample sizes (ranging between 3 and 15 participants) utilised a multiple baseline, single-case methodology (Raulston et al., 2019; Singh et al., 2006; Singh et al., 2014a; Singh et al., 2014b). Three studies employed a randomised control trial (RCT) methodology (Singh et al., 2016b; Singh et al., 2018; Weitlauf et al., 2020); while two studies employed a controlled pre- and post- design (Bethay et al., 2013; Corti et al., 2018). Of the remaining four studies, one was exploratory in nature and utilised a single-case design (Pess, 2016); one employed a multiple baseline, between-group design (Singh et al., 2019); one employed a pre-post within group design (Connolly, 2020) and one employed a single-case pre- and post- design (Singh et al., 2016a). Considering that these final

four studies do not include control groups, their function in addressing the review questions will necessarily be limited. Similarly, results from the four studies that utilised smaller sample sizes will also be presented with due caution.

Interventions

Six studies by Singh and his colleagues focussed on evaluating an intervention originally devised by that same team, namely, Mindfulness-based positive behaviour support (MBPBS). MBPBS teaches mindfulness-based practices, and subsequently teaches PBS within the context of mindfulness. In all six studies, MBPBS was delivered in an intensive, full-day training paradigm, with length of training ranging between 3 and 7 days. The seventh study by Singh et al. (2006) included in the review did not evaluate MBPBS; instead, it utilised a combined behavioural and mindfulness training intervention. Bethay et al. (2013) utilised a combined ACT and ABA intervention; similarly to MBPBS, this intervention places more focus on the MBI component of the dyad, namely, ACT. Corti and colleagues (2018) evaluated a combined ACT-infused parental training, with an early intensive behavioural intervention (EIBI). This intervention was delivered over 12 sessions, and was designed to teach participants the fundamental elements of ACT, such as acceptance, defusion, and committed action, as well as teaching behavioural management strategies. The intervention by Pess (2016) alternated ACT sessions with sessions based on behaviour training modules, designed for carers of children with ASD. Raulston and colleagues (2019) evaluated a combined MBI intervention with parent training for children with ASD, while Connolly (2020) evaluated a combined ACT and PBS intervention for carers of children with intellectual and developmental disabilities. Finally, the intervention evaluated by Weitlauf et al.

(2020) combined sessions in mindfulness-based stress reduction (MBSR) with the parent-implemented Early Start Denver Model (P-ESDM), which is an ABA-based intervention designed to support parents in the management of challenging behaviour. Of note, of the thirteen studies, this is the sole intervention that was more heavily based on the ABA component (12 weekly sessions of P-ESDM) as compared to the MBI component (6 sessions of MBSR).

The length of the interventions varied greatly between studies, ranging from 2 sessions (Corti et al., 2018), to the 12 sessions evaluated in Raulston et al.'s (2019) study. Furthermore, some studies used follow-up sessions after the intervention was completed, while others did not. Due to the variations in intervention length and structure, coupled with differences in the age range of the target population, any direct comparison of treatment effects between studies should be undertaken with caution.

Outcome measures

The outcome measures used also varied greatly. Please refer to Table 1. for a full list of outcome measures. Despite said variation, however, the outcome measures employed almost invariably looked at changes in psychological wellbeing, particularly stress, and at changes in frequency of challenging behaviour. Three studies moreover evaluated changes in mindfulness (Corti et al., 2018; Raulston et al., 2019; Weitlauf, et al., 2020), including concepts associated with specific treatment modalities, such as cognitive fusion in ACT. An interesting further viewpoint on treatment effectiveness is provided by Singh and colleagues, who

analysed the cost-effectiveness of employing combined MBI and ABA interventions in residential settings (Singh et al., 2014b; 2016a; 2016b; 2018).

Quality assessment

A total of seven studies was assessed as being of high quality in terms of their methodology. A summary table of all quality elements assessed is presented in Table 2.

Table 2. Quality assessment of reviewed studies.

Study	Betha y et al., 2012	Conn olly, 2020	Corti et al., 2018	Pess , 2016	Raulsto n et al., 2019	Sing h et al., 2006	Singh et al., 2014 a	Singh et al., 2014 b	Singh et al., 2016a	Singh et al., 2016b	Sing h et al., 2018	Singh et al., 2019	Weitl auf et al., 2020
1. Is the hypothesis/aim/objective of the study clearly described?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
2. Are the main outcomes to be measured clearly described in the Introduction or Methods sections?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
3. Are the characteristics of the patients included in the study clearly described?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
4. Are the interventions of interest clearly described?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?	yes	no	yes	yes	no	no	no	no	no	no	no	no	no
6. Are the main findings of the study clearly described?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
7. Does the study provide estimates of the random variability in the data for the main outcomes?	yes	no	yes	no	yes	yes	no	no	yes	no	no	no	yes
8. Have all important adverse events that may be a consequence of the intervention been reported?	no	no	yes	no	no	no	no	no	no	no	no	no	no
9. Have the characteristics of patients lost to follow-up been described?	no	no	yes	yes	yes	yes	yes	yes	yes	yes	no	no	yes
10. Have actual probability values been reported (e.g. 0.0035 rather	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes

than <0.05) for the main outcomes except where the probability value is less than 0.001?													
11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	yes	CD	CD	CD	no	no	no	no	yes	no	yes	yes	no
12. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	yes	CD	CD	CD	no	no	CD	CD	CD	no	yes	yes	no
13. Were the staff, places, and facilities where patients were treated, representative of the treatment the majority of patients received?	NA	yes	NA	no	no	yes	no	yes	yes	no	yes	yes	yes
14. Was an attempt made to blind the study subjects to the intervention they have received?	no	no	no	no	no	no	no	no	no	no	no	no	no
15. Was an attempt made to blind those measuring the main outcomes of the intervention?	no	no	no	no	no	no	no	no	no	no	no	no	yes
16. If any of the results of the study were based on "data dredging", was this made clear?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention	yes	yes	yes	yes	yes	no	no	no	no	no	yes	yes	yes

and outcome the same for cases and controls?													
18. Were statistical tests used to assess the main outcomes appropriate?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
19. Was compliance with the intervention/s reliable?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	no
20. Were the main outcome measures used accurate (valid and reliable)?	yes	yes	yes	no	yes	yes	yes	yes	yes	yes	yes	yes	yes
21. Were the patients in different intervention groups (trials and cohort studies) or were the cases and control (case-control studies) recruited from the same population?	yes	yes	yes	yes	yes	yes	no	yes	yes	yes	yes	yes	yes
22. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	CD	yes	CD	CD	CD	CD	CD	CD	CD	CD	CD	yes	yes
23. Were study subjects randomised to intervention groups?	yes	no	no	no	NA	no	no	no	no	yes	yes	no	yes
24. Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	CD	NA	NA	NA	NA	NA	NA	NA	NA	CD	CD	NA	CD
25. Was there adequate adjustment for confounding in the analyses from	yes	NA	yes	NA	NA	no	no	no	no	no	no	no	no

which the main findings were drawn?													
26. Were losses of patients to follow-up taken into account?	no	no	yes	yes	yes	yes	yes	yes	yes	yes	yes	NA	yes
27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	no	yes	yes	NA	NA	NA	NA	NA	NA	CD	CD	yes	yes
Total quality of Reporting	9	6	11	9	9	9	8	8	9	8	7	7	9
Total quality of Methodology	<u>10</u>	<u>9</u>	<u>9</u>	6	7	7	6	7	<u>8</u>	7	<u>11</u>	<u>11</u>	<u>11</u>

Key: P = Partially, NA = Not applicable, NR = Not reported, CD = Cannot determine

Note: Total scores highlighted in **bold** denote high-quality papers

Main findings

Of the thirteen studies reviewed, seven appear to have the strongest methodological designs, as rated by the current reviewers (Bethay et al., 2013; Connolly, 2020; Corti et al., 2018; Singh et al., 2016a, 2018, 2019; Weitlauf et al., 2020). While useful indications can be drawn from the remaining six studies, the main findings presented below are primarily based on those studies that are methodologically stronger.

A total of ten studies looked at changes in carer stress following intervention. Of these, nine studies, including four with methodologically stronger designs and larger sample sizes (Bethay et al., 2018; Singh et al., 2016b; Singh et al., 2018; Weitlauf et al., 2020), reported significant reductions in carer stress, either as compared to an ABA-based intervention alone, or as measured by a multiple baseline single-case methodology. The tenth study (Corti et al., 2018) reported a decrease in carer stress post treatment approaching statistical significance ($p = 0.06$). These results suggest that combined MBI and ABA interventions are particularly effective at reducing carer stress. Moreover, there appears to be a strong indication that combined MBI and ABA interventions are effective at reducing carer stress as compared to ABA interventions alone (Singh et al., 2016b; Singh et al., 2018; Weitlauf et al., 2020). Of interest, in their study on paid carers for adults with intellectual disabilities, Bethay and colleagues (2013) highlighted that a combined MBI and ABA intervention was particularly effective for those carers who showed more psychological distress at baseline. Conversely, severity of diagnosis was not found to be predictive of treatment effectiveness in a community study of parents of children with ASD (Weitlauf, et al., 2020). Weitlauf and colleagues (2020) further reported that, despite there being a significantly greater reduction in carer stress in their combined MBI and ABA intervention, compared to an ABA-based intervention alone, there was no

significant between-group differences in changes to depression, anxiety, or life satisfaction.

Two of the reviewed studies examined changes to mindfulness (Weitlauf et al., 2020; Corti et al., 2018), with only Corti's study (2018) reporting a statistically significant change post-treatment, specifically, a significant reduction in mindfulness awareness in carers ($p < .01$). The authors of the study describe the result as paradoxical, however, it should again be noted that increasing mindfulness skills is a complex, non-linear endeavour, with scholars hypothesising that mindfulness skills likely develop long after the normal duration of MBI interventions (Singh, et al., 2006), and that, therefore, marked differences between pre- and post-measures should not be expected. Furthermore, caution should be applied when interpreting measures of mindfulness awareness, as these often utilise frequency of non-mindful behaviours as a measure of mindful awareness. The issue with this type of measure is that, following mindfulness training, one can be expected to be more able to recognise their non-mindful behaviour, thus appearing, on the surface, as entertaining non-mindful behaviour more frequently, while in reality they may simply be more able to notice it.

All studies that looked at changes in frequency of challenging behaviour, including two studies employing RCT designs with large sample sizes, reported that challenging behaviour decreased significantly following combined MBI and ABA interventions (Singh, et al., 2006; Singh et al., 2014b; Singh et al., 2016a; Singh et al., 2016b; Singh et al., 2018). Furthermore, two high quality studies reported that said decrease was significantly greater following a combined MBI and ABA intervention, compared to an ABA-based intervention alone (Singh et al., 2016b; Singh et al., 2018). Similarly, and perhaps more strikingly, in their study of paid

carers working with adults with severe and profound developmental disabilities, Singh and colleagues (2006) reported that the frequency of challenging behaviour did not decrease following an ABA-based intervention, but did decrease following mindfulness training. This finding should however be assessed with caution given the low methodological quality and small sample size of the study.

Finally, out of the four studies that looked at cost-effectiveness (Singh et al., 2014b; Singh et al., 2016a; Singh et al., 2016b; Singh et al., 2018), all four reported marked reductions in cost to care providers following the implementation of a combined MBI and ABA intervention. This provides a strong indication of cost-effectiveness, considering that two studies out of the four utilised an RCT methodology with large sample sizes (Singh et al., 2016b; Singh et al., 2018). Savings to the overall running cost of the service ranged from 78% to 89.27%, with one methodologically strong study reporting savings as high as 0.5 million USD for the care provider (Singh, et al., 2018).

Discussion

To date, literature has focussed on evaluating the efficacy of either ABA- or MBI-based interventions designed to ameliorate the psychological wellbeing and quality of life of carers of people with developmental disabilities. The present systematic review adds to the evidence base by examining the efficacy of a novel set of interventions, namely, combined ABA- and MBI-based interventions. In addition, the review seeks to evaluate whether combined ABA- and MBI-based interventions are more efficacious at increasing the psychological wellbeing and quality of life of carers than ABA-based interventions alone.

Overall, evidence suggests that combined ABA- and MBI-based interventions are conducive to positive psychological changes in carers, particularly when facilitated over longer periods of time, and when implemented consistently. A majority of reviewed studies reported that carers experienced significant decreases in stress following combined interventions, including studies that employed high-quality RCT designs and large sample sizes. Only one high-quality study did not report a significant reduction in stress following the combined intervention; however, it did highlight a convincing trend towards statistical significance ($p = 0.06$; Corti et al., 2018).

Furthermore, studies that looked at changes in frequency of challenging behaviour reported a significant decrease in challenging behaviour following combined interventions. Models of carer-dependant interaction within the field of developmental disabilities suggest that suboptimal psychological wellbeing in carers results in increased frequency of challenging behaviour, leading to further carer distress (e.g.,

Hastings, 2002), and that, therefore, frequency of challenging behaviour can be tentatively used as a marker of psychological wellbeing and quality of life in carers.

Finally, studies that looked at whether combined interventions increased carers' mindful behaviour did not highlight any significant change post intervention. To account for this, it can be argued that changes to mindful behaviour cannot be detected within the relatively short timeframes of experimental evaluation, which raises questions about the validity of some measuring methodologies.

In relation to the secondary review question, evidence suggests that combined ABA and MBI-based interventions are significantly better at reducing carer stress, decreasing the frequency of challenging behaviour and at reducing running costs of residential care settings, than ABA-based interventions alone. Albeit by no means extensive, existing literature all points to combined interventions being superior to a stand-alone ABA counterpart, both for paid and unpaid carers, and within both children and adult contexts. Such indication of treatment superiority comes as no surprise when considering models of carer and dependant interdependency, as interventions aimed at simultaneously supporting both carers (MBI) and their dependants (ABA) appear to operate cumulatively, with increased carer wellbeing resulting in increased dependant wellbeing, and vice-versa.

Limitations

Of the thirteen studies reviewed, eleven were based in the United States, which limits the generalisability of findings to other social realities. Nonetheless, models of carer stress suggest that the psychological impact of caring for people with developmental disabilities is universal, a notion that is supported by the existence of

evidence-based cross-national and cross-cultural intervention programmes, such as the Mental Health Gap Action Programme operated by the World Health Organisation (WHO, 2017).

A second limitation is that all studies looking at adults with developmental disabilities were based on residential care settings. The efficacy of combined interventions may thus differ when implemented elsewhere, such as in community settings. Similarly, all studies that looked at children with developmental disabilities were based on samples taken from a community setting only, which again limits the representativeness of the studied sample. Moreover, all high-quality, children-based studies included in the review are based on ASD diagnoses, which are but a segment of developmental disabilities.

A further limitation to the present review lies in the heterogeneity of intervention types, their length, and in the variable presence of follow-up treatment sessions. Specifically, most but not all interventions placed greater emphasis on their MBI component; ranged between 2 and 12 sessions in length; and not all included follow-up sessions. Articulating a unified summary of results, as well as any direct comparison between combined interventions, would therefore be unwarranted at this stage.

Finally, one of the interventions included in the review (MBPBS) was both devised and evaluated by members of the same team (Singh et al., 2014a; 2014b; 2016a; 2016b; 2018; 2019), a practice that can be subject to confirmation bias.

Implications and future directions

Future research should aim to evaluate combined ABA- and MBI-based interventions in countries other than the United States; in settings other than residential for adults with developmental disabilities, and other than community for children with developmental disabilities; and for developmental disabilities other than ASD in children. Furthermore, as the evidence base increases, future reviews may benefit from grouping together studies evaluating interventions of similar type and length, and comparing their effectiveness in ameliorating the psychological wellbeing and quality of life of carers of people with developmental disabilities. A wider literature on the subject is moreover likely to mitigate biases such as confirmatory bias. Lastly, future research should aim to compare combined interventions with MBI-based interventions on carer psychological wellbeing and quality of life, as the present review only identified studies that utilised ABA-based interventions as controls. Such comparison may in turn help elucidate the elusive mechanisms of MBIs, including how to best measure changes in mindful behaviour.

Conclusion

The systematic review highlighted that there is emerging evidence that combined ABA- and MBI-based interventions can be effective in reducing carer stress, and frequency of challenging behaviour within the context of developmental disabilities. Evidence moreover suggests that combined interventions may be superior in these domains to interventions based solely on ABA, and may be more cost-effective than their ABA counterparts when used in residential care settings. Ultimately, however, not enough data on combined ABA- and MBI-based interventions exists to make

definitive recommendations for its use in clinical settings, with more high-quality studies needed to test its effectiveness.

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**A realist evaluation of a combined Acceptance and commitment therapy and
Positive behaviour support intervention for carers of children with intellectual
disabilities**

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Abstract

Background: There is a developing evidence base regarding the effectiveness of combined Applied behaviour analysis and Mindfulness-based interventions aimed at carers of children with intellectual disabilities. Not much however is yet known about precisely which elements of such combined interventions work for which carers, why, and under what environmental circumstances.

Methods: The study utilised a realist evaluation approach to examine a combined Positive behaviour support and Acceptance and commitment intervention for carers of children with intellectual disabilities. Quantitative data on the effectiveness of the studied intervention was compared against: a) the existing evidence base; and b) two sets of qualitative interviews, one conducted with thirteen carers who had participated in the intervention trial, and the other with six experts of the treatment modality and target population. Through this comparison, a series of schematic representations was generated, known as a context-mechanism-outcome configurations, to illustrate the necessary conditions for the intervention to achieve the desired outcomes.

Results: Results posit that, in order to decrease the psychological distress of carers, and increase their psychological flexibility, combined interventions should merge the two psychological approaches in a truly unitary format. Furthermore, in order to sustain desired outcomes over time, carers should be offered ongoing mentoring and support, and should operate in adequately resourced environments. In addition, it is hypothesised that the creation of a shared vocabulary between all elements of the child's system can increase carers' openness to practice newly acquired skills.

Conclusion: Future research should develop interventions that truly merge principles of Positive behaviour support with those found in Acceptance and commitment therapy, and test their efficacy against comparable iterations of the intervention. Furthermore, the creation of adequately resourced living and working environments should be tested, to examine whether these foster the acquisition and practice of new skills.

Keywords: Realist evaluation, positive behaviour support, acceptance and commitment therapy, intellectual disabilities, carers, combined intervention.

Introduction

Caring for children with intellectual disabilities is a rewarding, albeit often demanding endeavour (Carr et al, 2016). Research shows that parents of children with intellectual disabilities present with higher rates of psychological distress, including anxiety and depression, as compared to parents of children without intellectual disabilities (Gupta, 2007; Olsson & Hwang, 2001). The impact of care on psychological wellbeing has moreover been observed in those who provide paid care to these children, including teachers in special education needs (SEN) schools. Evidence suggests that SEN teachers are more impacted by work-related stress than their mainstream school counterparts (Kokkinos & Davazoglou, 2009), with one influential study reporting that 50% of SEN teachers meet criteria for depression (Biglan, Layton, Jones, Hankins, & Rusby, 2013). Moreover, children with intellectual disabilities often present with higher emotional, educational, and physical needs as compared to their neurotypical peers (Carr, Linehan, O'Reilly, Noonan Walsh, & McEvoy, 2016), while SEN teachers often lack access to adequate support in their workplace (Rose, Madurai, Thomas, Duffy, & Oyebode, 2010), and can be subject to understaffing and other structural difficulties such as inconsistent, outdated, and even inexistent training opportunities (Noone, personal communication). This can lead SEN teachers to experience a wider array of stress-inducing factors, as well as, unsurprisingly, increased rates of work-related burnout (Devereux, Hastings, Noone, Firth, & Totsika, 2009).

Aside from having increased needs, it has been reported that as many as one in ten people with an intellectual disability display challenging behaviour (Lowe et al.,

2007), particularly at the more severe end of the disability spectrum (Carr et al., 2016). Challenging behaviour is defined as a “behaviour that puts the individual or others at risk and/or could lead to the limitation of an individual’s access to their community” (British Psychological Society, 2018). When managed ineffectively, it can lead to difficulties both at home and at school, and it has been linked to increased anxiety, and depression in parents (Hastings, 2002), who often overlook their own psychological needs in favour of those of their children (Murphy, Christian, Caplin, & Young, 2007). Similarly, challenging behaviour has been shown to increase psychological distress in staff (Jenkins, Rose, & Lovell, 1997). It follows that challenging behaviour adds an important dimension to the study of psychological wellbeing of teachers and parents, as parents and teachers who experience increased psychological distress in turn become less well equipped to manage challenging behaviours, leading to a direct increase in such behaviours (McConnell & Savage, 2015). This creates a vicious cycle of fatigue, ineffectiveness, and frustration, a cycle fuelled by the bi-directional and self-reinforcing effects that challenging behaviour imposes on the relationship between child and carer (Hastings, 2002).

Interventions aimed at managing challenging behaviour

In light of the significant implications for the psychological wellbeing of both children and their carers that arise from ineffective management of challenging behaviour, it should come as no surprise that interventions aimed at managing challenging behaviour abound, most notably, those derived from applied behaviour analysis (ABA). A prominent and widely implemented ABA-based intervention for the management of challenging behaviour is positive behaviour support (PBS). PBS is a

multi-linear intervention (LaVigna & Willis, 2005), in the sense that it is not restricted to a simple analysis of behaviour, its antecedents, and its consequences; rather, it aims to build a comprehensive analysis of the environment within which challenging behaviour emerges. As such, the aim of PBS is to modify those aspects of the environment that have been determined as causal factors for challenging behaviour, such as ineffective communication of needs, or behavioural triggers, and propose both reactive and proactive management strategies. While reactive strategies are designed to be implemented at times of distress to decrease the episodic severity of challenging behaviour (LaVigna, Willis, & Koegel, 2005), proactive strategies aim to adapt the environment to best suit the attitudes and behaviours of the person, thereby reducing the frequency of challenging behaviour (Carr et al., 2016). PBS can therefore be construed as a technique aimed at increasing the repertoire of possible behavioural responses of the person with intellectual disabilities, through an appreciation that challenging behaviour is, in essence, a way of communicating distress and unmet needs, rather than a behaviour that needs to be controlled (Carr et al., 2002). Ultimately, PBS aims to improve the quality of life of the person receiving the intervention, with researchers identifying as many as eight dimensions to quality of life relating to the successful implementation of this intervention: emotional wellbeing, interpersonal wellbeing, material wellbeing, personal wellbeing, physical wellbeing, self-determination, social inclusion, and rights (Kincaid, Knoster, Harrower, Shannon, & Bustamante, 2002).

[Interventions aimed at supporting the psychological wellbeing of carers](#)

Parallel to interventions aimed at increasing the quality of life of children with intellectual disabilities are interventions which focus on increasing the psychological

wellbeing of carers. The theoretical basis for the efficacy of this class of interventions is two-fold: on the one hand, it stems from the recognition that poor psychological wellbeing in carers directly increases challenging behaviour in children in a self-reinforcing fashion (Hastings, 2002). On the other hand, it is grounded in a systemic framework, which, in similar fashion to PBS, aims to equip the system around the child (primarily, their carers) with an increased degree of psychological resilience, compassion, and understanding of the child's needs. In addition, mindfulness-based interventions aimed at people with intellectual disabilities are also currently being evaluated. The evidence for these interventions in adults is promising (Idusohan-Moizer, Sawicka, Dendle, & Albany, 2015), particularly when offered in a group format (Beauchemin, Hutchins, & Patterson, 2008; Croom, Chadwick, Nicholls, & McGarry, 2021); however, some researchers point to difficulties in comprehending the aims of mindfulness as a possible obstacle (e.g., Griffith et al., 2019). This is an important question given the complexity of teaching mindfulness skills, as the same difficulties may arguably be encountered by neurotypical participants. Furthermore, based on the notion that MBIs adapted for the child population are as effective as interventions designed for adults, especially when aimed at symptoms of depression and anxiety (Dunning et al., 2018), we may hypothesise that the key to optimal treatment response lies in how MBIs are adapted to participants with differing cognitive skills and at different stages of development.

The current view on the effectiveness of third-wave- and mindfulness-based interventions (MBIs) for carers of children with intellectual disabilities suggests that such interventions are indeed efficacious in decreasing psychological distress in parents (Osborn, Dorstyn, Roberts, & Kneebone, 2021; Rayan & Ahmad, 2018). Conversely, the efficacy of such interventions in SEN teachers remains to be

determined. A pilot randomised controlled trial of Acceptance and commitment therapy (ACT) for pre-school SEN teachers found that the intervention increased teachers' levels of acceptance and mindfulness (Biglan et al., 2013), although it did not report any significant decrease in depression. Further evidence on the effectiveness of using MBIs in this population comes from a case series that employed a small sample of SEN teachers, and which highlighted a reduction in challenging behaviour following the intervention (Singh, Lancioni, Winton, Karazsia, & Singh, 2013). Finally, there have been promising indications that MBIs can reduce stress in support staff for adults with intellectual disabilities (Noone & Hastings, 2009; 2010), leading to a need to further explore the efficacy of MBIs in the SEN teacher population.

Combining ABAs and MBIs

Considering the need to provide effective, behaviourally-based interventions for children with intellectual disabilities, and the concomitant need to support the psychological wellbeing of their carers, interventions which combine ABAs and MBIs have attracted considerable interest in the past decade. Evidence to date suggests that such combined interventions are at least as effective, and in some cases superior to ABAs in terms of reducing the frequency of challenging behaviour (Singh et al., 2016, 2020), and in ameliorating the psychological distress of carers (Bethay, Wilson, Schnetzer, Nassar, & Bordieri, 2013; Connolly, 2020; Corti et al., 2018; Raulston et al., 2019; Weitlauf et al., 2020). However, aside from the encouraging data supporting the efficacy of such combined interventions, a comprehensive understanding of how to best combine ABIs with MBIs is yet to be achieved, including in relation to optimal treatment length, modality, and setting.

The realist evaluation approach

The design of the present study is modelled on the realist evaluation (RE) approach, a constructivist, generative approach originally designed to determine why a given social intervention works, for whom it works, and under what circumstances it does so (Pawson & Tilley, 1997; p. 57). To the author's knowledge, no study to date has conducted a realist evaluation of combined ABA and MBI interventions for carers of people with intellectual disabilities. The present study therefore aims to add to the existing literature by proposing a working model of why, and how such combined interventions work.

Realist evaluation is constructivist in that it is based on a continual exchange of information between the main "*actors*" associated with the intervention, most commonly those who design it, those who facilitate it, and those who participate in it. Other actors can also be included in the discourse, for example project managers, experts, or policy makers. The exchange of information between actors is normally facilitated through semi-structured interviews, as is the case in the present study. In addition, information can also be drawn from literature reviews, as well as from quantitative data.

Realist evaluation is moreover generative in that it seeks to establish a "*real connection between variables of interest*" (Pawson & Tilley, 1997; p. 33). Much of the current research within social sciences, including psychology, resides in a successionist, rather than generative, approach to drawing causal associations between variables. A crude simplification of the successionist logic is that, if dependent variables are effectively isolated, such as via randomly assigning identical participants to two conditions which differ in only one aspect (randomised, case – control design), then any difference in outcome can be attributed to the difference

between the two conditions. A crucial point however is that causation cannot be directly observed, only its effect can. To illustrate, suppose one group of participants is exposed to an intervention, and a reduction in psychological distress is observed, while a second group of identical, randomly assigned subjects is not exposed to the intervention, and no change in psychological distress is detected. A causal inference can then be drawn between the intervention and the change in psychological distress. The realist evaluation logic however suggests that within a successionist approach, the mechanisms of change remain unknown, in other words, no indication is provided as to why the intervention produced the observed change in psychological distress – only that it did.

This is an important distinction, as while statistical methods that elucidate causation do exist in successionist research, they can only elucidate *how* an intervention works, not *why* it worked. From a clinical standpoint, understanding how an intervention works can lead to optimisations in treatment effectiveness, treatment dosage, and similar constructs. Conversely, understanding the *why* allows researchers to adapt an intervention to different settings and populations. Using a different example to illustrate this distinction, suppose that attending a pre-school breakfast club results in an increase in the pupil's proficiency in school. Using a successionist approach, quantitative data on the relationship between the breakfast club, and the increase in school proficiency may be established. A causal relationship between the breakfast club and the outcome of increased proficiency in school may then be determined, for example, through regression or mediation analyses. A generative approach, on the other hand, would aim to determine why attendance to a breakfast club generates increased proficiency at school.

Researchers may hypothesise that better nutrition leads to increased computational

power in children; or that children are able to settle better after pre-school socialisation, leading to increased focus in the classroom; or that children socialising with peers at the breakfast club generates peer affiliation, leading to increased self-esteem and ultimately self-belief in achieving in school, and so on. Therefore, the generative approach is concerned with generating hypotheses on the potential mechanisms that are responsible for the observed outcomes (Pawson & Tilley, 1997), and subsequently testing the validity of said hypotheses. This is usually achieved through a combination of literature review (in the breakfast club example, literature relating to nutrition, socialisation, and classroom proficiency), quantitative data (grades, attendance records), and, crucially, through eliciting the views of the relevant actors (the children themselves, the teachers, parents, and so on).

A final consideration regarding the RE method is that it is theory-driven, that is, it seeks to refine the theory underpinning a given social intervention. This mechanism of theory refinement is based on the model of scientific enquiry introduced by Wallace (1971), known as the Wheel of science, which proposes that in order to test a theory driving a given intervention, one must first form testable hypotheses, collect observations, and finally derive empirical generalisations. Generalisations are then compared against the theory, which is revised whenever observations and relative generalisations do not conform with the original theory. The realist evaluation method differs from Wallace's model of enquiry in that observations lead to specifications of the intervention, rather than empirical generalisations. In other words, observations seek to inform what works for whom (*mechanisms*) under which circumstances (*contexts*), allowing the intervention to remain flexible to being adapted to different settings. Going back to the breakfast club example, if researchers establish that better nutrition is what drives increased proficiency in

school (*mechanism*), then schools which are not able to facilitate such clubs (*context*) can encourage families to promote healthy nutrition instead.

Current study

The current study builds on the research conducted by Connolly (2020), who evaluated a novel ACT and PBS intervention for teachers and parents of children with intellectual disabilities. Her study provides preliminary support for the intervention, with results suggesting that it can decrease stress, anxiety, and depression in both sets of carers. Not much however is known about precisely how the intervention achieves such positive outcomes. The current study therefore aims to address the following research question:

- *What are the potential mechanisms and contexts via which a combined ACT & PBS intervention for parents and SEN teachers of children with intellectual disabilities works to achieve the outcomes of said intervention, namely:*
 - *decreased psychological distress in carers;*
 - *increased self-efficacy in managing challenging behaviour;*
 - *decreased burnout;*
 - *and increased psychological flexibility in carers?*

As noted above, successionist research evaluating combined ACT and PBS interventions is currently flourishing; however, to the author's knowledge, no generative, realist evaluation currently exists on combined ACT and PBS interventions. The present study thus aims to increase our understanding of what works for whom, why, and under what circumstances, with respect to combined ACT and PBS interventions for carers of children with intellectual disability.

Methods

Design

The design of the present study is modelled onto the realist evaluation approach, a theory driven, mixed methods approach that aims to examine why an intervention works, for whom it works, and under which circumstances it does so (Pawson & Tilley, 1997). To address the study's research question using the realist evaluation approach, first, a programme theory for the intervention, known as initial programme theory (IPT), was generated. Second, the initial programme theory was tested against a second set of qualitative data, as well as against a set of quantitative data, which led to a refined version of the programme theory, known as middle-range programme theory (MRPT). Each of the two processes of programme theory generation and refinement is described below.

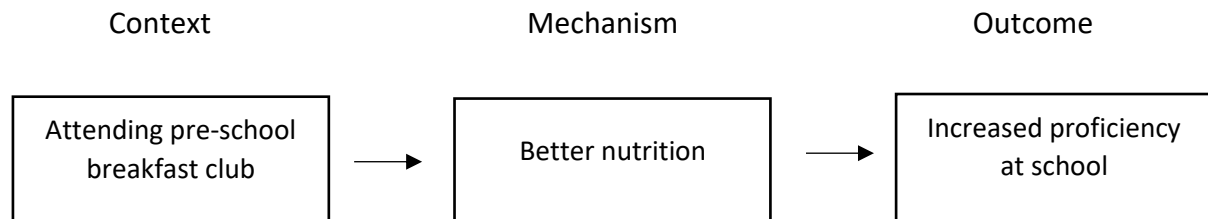
Given that programme theories are not intended to be definitive, an MRPT can be further refined with any subsequent set of evidence, to produce an increasingly comprehensive understanding of which elements of a given intervention work for whom, and under which circumstances. Directions on future MRPT refinements are presented in the discussion chapter.

Initial programme theory

Constructing a programme theory using a realist evaluation approach is an iterative process (Fick & Muhajarine, 2019). At the start of the process, an initial programme theory was compiled, based on literature reviews and qualitative data, and schematised in the form of Context-Mechanism-Outcome configurations, or CMOs.

An example of a CMO configuration, based on the breakfast club scenario is presented below.

Table 1. An example of a CMO configuration.



The literature review on combined ACT and PBS approaches, their efficacy, and their proposed mechanisms of action was undertaken by a different author (Connolly, 2020), who formulated four hypotheses in her study based on said review. Specifically, the study by Connolly (2020) hypothesised that the combined ACT and PBS intervention would lead to:

- 1) a reduction in psychological distress in teachers and parents attending the intervention;
- 2) an increase in self-efficacy in parents and teachers in managing the children's challenging behaviour;
- 3) a reduction in burnout in parents and teachers; and
- 4) an increase in psychological flexibility in parents and teachers.

The second step in constructing the IPT entailed comparing the four hypothesized outcomes of the intervention with a set of qualitative data, namely, interviews, undertaken with those who participated in the intervention's pilot study. Of note, the questions posed by Connolly (2020) to her participants did not seek to directly confirm, or refute, the hypothesised outcomes of the intervention, as per the classic

realist evolution approach of IPT construction. Instead, the interviews were structured as a series of open-ended questions aimed at eliciting the participants' views on the social validity and the perceived effectiveness of the intervention. This is due to the fact that Connolly's study (2020) did not employ a realist evaluation design; rather, it sought to evaluate quantitatively the effectiveness of the piloted intervention, and to elicit participants' views on said effectiveness. However, given the richness of qualitative data collected through the interviews, and its pertinence to the process of IPT construction, it was deemed appropriate to analyse and utilise the data for the scope of constructing the IPT. By comparing the four hypotheses with the interview data, the present study developed an IPT, and distilled it into three CMOs, denominated CMO 1, 2, and 3.

Middle-range programme theory

After the initial programme theory had emerged, in line with the realist evaluation process of continual programme theory refinement (Pawson & Tilley, 1997), a middle-range programme theory was developed. As opposed to initial programme theories, which only provide tentative frameworks of how interventions work, middle-range programme theories are designed to create generalisable findings (Byng, Norman, & Redfern, 2005), by outlining in more detail how different contexts and mechanisms allow the intervention to be efficacious.

First, the initial CMOs (CMOs 1, 2, and 3) were mapped against a set of quantitative data evaluating the effectiveness of the intervention. The quantitative data was obtained by Connolly in her precursor study through a battery of self-report outcome measures, administered at pre-, post-, and 6-week follow-up (Connolly, 2020). This

process of comparison highlighted four discrepancies between: a) the hypothesised outcomes of the intervention (hypotheses 1, 2, 3, and 4); b) the subjective accounts of the participants (qualitative data); and c) the objective measures completed by the participants (quantitative data). Specifically, the four discrepancies were:

- i) a perceived increase in self-efficacy in managing challenging behaviour reported qualitatively, that was not consistent with the quantitative data on self-efficacy which indicated this was not maintained at 6 weeks' follow-up;
- ii) participants reporting an increase in job satisfaction in qualitative data, without a concomitant improvement in work-related and personal-related burnout as measured by the quantitative data;
- iii) teachers reporting no change in how consistently PBS plans were implemented, which was contrary to what the IPT hypothesised (namely, that there will be an increase in the consistency of PBS plan implementation in both teachers and parents following the intervention);
- iv) teachers reporting no change in attitude towards mindfulness practice, which was again contrary to what the IPT hypothesised (namely, that the intervention would result in changes in attitudes towards mindfulness practice in both teachers and parents).

Second set of qualitative interviews

As the process of comparison highlighted that the quantitative data did not support all of the configurations laid out in CMOs 1, 2, and 3, a second set of interviews, this time with experts in the fields of ACT, PBS and intellectual disabilities, was

undertaken. Experts were asked their views in relation to the above discrepancies, on the basis of both their clinical experience, and theoretical understanding of the interventions (ACT and PBS) and target group. The interviews were then analysed to determine which aspects of the programme theory would be amenable to refinement (see Appendix D for a full list of interview questions). As a result, the three CMOs that comprised the IPT were refined in the following manner: CMO 4 merged and expanded on CMOs 1 and 2; CMO 5 expanded on CMO 3; while CMO 6 proposes an entirely new configuration.

In terms of interview data analysis, interview extracts and themes were identified, analysed, and grouped as either contexts, mechanisms, or outcomes, using a standard thematic analysis process (Saldana, 2016). Each grouping of themes was subsequently corroborated with findings from the literature review (for CMOs 1, 2 and 3), or with findings from the quantitative dataset (for CMOs 4, 5, and 6), in a process known as “*linked coding*” (Jackson & Kolla, 2012). As such, the process of programme theory generation was achieved “*by moving backward and forward among empirical data, research literature, and emergent theory*” (Dey & Teasdale, 2013, p. 255).

Ethical approval

The School of Health in Social Science, University of Edinburgh, granted ethical approval for the analysis of Data A, that is, the interviews conducted by Connolly in her study (Appendix A), as well as approval to conduct a second set of interviews with experts in the fields of ACT, PBS, and intellectual disabilities (Data B). (Appendix B).

Participant recruitment

First set of interviews, teachers and parents

In the study by Connolly (2020), prospective participants meeting the inclusion criteria for the studied intervention and subsequent interviews (namely, caring for or teaching a child with an intellectual disability; speaking fluent English; and not having a diagnosis of intellectual disability) were identified by clinicians working at a National Health Service (NHS) Child intellectual disability service in Scotland, UK, and by senior educational staff working at special education needs schools in the same area. Of the 37 participants recruited for the study (18 parents, 19 teachers), a total of 22 completed the intervention. Of these, 13 (5 parents, 8 teachers) attended the interviews. The interviews were undertaken six weeks after the intervention had finished, either individually or in group format (2 parents individually, 3 parents in a group, and 2 groups of 4 teachers). Themes from the interviews were broadly coded and conveyed in a summary table, although a more extensive analysis was not undertaken. The present study undertook a second coding and analysis of the transcripts, following the programme theory generation and data analysis methods described above.

Second set of interviews, experts

The second set of interviews entailed interviewing experts in the fields of ACT, PBS, and or intellectual disabilities. These were recruited through a message posted on an online special interest group focussed on the application of behavioural sciences (including ACT and PBS) within the context of intellectual disabilities. Experts were also identified through discussions with the research collaborators, or through reviewing relevant publications, and invited to participate via publicly listed emails.

In light of the restricted timeframe for data collection, purposive sampling was used to identify the optimal minimum of experts to be invited to the interviews. The sampling process identified a total of 6 interviewees, namely, two experts on PBS, two experts on intellectual disabilities and ACT, and two experts on ACT without expertise in intellectual disabilities. Experts in PBS were all assumed to have expertise in intellectual disabilities.

For the purposes of the study, expertise was defined as meeting one or more of the following criteria:

- Having a doctorate focussing on either ACT, PBS, or DDs.
- Having facilitated a lecture on either ACT, PBS, or DDs at university level in the past 10 years.
- Having supervised a doctorate level research project in ACT, PBS, or DDs.
- Having published a paper in either ACT, PBS, or DDs in a peer-reviewed journal.
- Having provided service development consultancy in either ACT, PBS, or DDs related projects.

Experts working full-time as NHS clinicians in the UK were not approached on the basis of the intense staffing requirements imposed by the COVID-19 pandemic; while experts working as NHS clinicians part-time, and clinicians not working in the UK were all approached. A total of four clinicians and two university faculty members were ultimately recruited.

Prospective participants were invited to read a document summarising the aims and inclusion criteria for the study online, through the JISC media platform. Participants

were asked to indicate their consent to participate, before being asked to indicate via email whether they met the inclusion criteria for the study. Interviews were then undertaken individually with the author, using a videoconferencing platform. The interviews were audio-recorded, anonymised and transcribed by the author, and subsequently analysed via the same programme theory generation and data analysis process used with the first set of interviews. Before the data was analysed, interview transcripts were reviewed by a second researcher, to ensure anonymity of participants.

A summary table (Table 2) of data collected though of the two sets of interviews is presented below.

Table 2. Participants and data.

	1st set of interviews	2nd set of interviews
Participant type	Teachers and parents	Experts
Number of participants approached	22	7
Number of participants interviewed	13 (8 teachers; 5 parents)	6
Type and focus of the interview	Semi-structured; Focus on the acceptability of the intervention	Semi-structured; Focus on refining CMOs 1, 2, and 3.
Format of interview	Individual (N=2) or group (N=11)	Individual

Semi-structured interviews

The semi-structured interviews with teachers and parents, undertaken by Connolly and her team (2020), were based on assessing the social validity and acceptability of the studied intervention. They included questions around what the participants felt

worked well in the intervention, what did not, and suggestions for improvement. Therefore, the interviews did not explicitly seek to elicit information around what the interviewees thought of the initial programme theory, as is recommended in the realist evaluation approach (Pawson & Tilley, 1997).

Conversely, the semi-structured interviews undertaken in the second set of interviews with experts were used to generate conversations around the initial programme theory and relative CMOs (CMO 1, 2, and 3). Specifically, experts were asked to comment on whether the initial programme theory was aligned with their experience and theoretical understanding of the relevant interventions and population. Experts were moreover asked to comment on predicted outcomes that were not observed in the pilot study, thus helping to recalibrate the programme theory, ultimately leading to middle-range programme theory, and consequently a new set of refined CMOs (CMO 4, 5 and 6).

Results

Initial programme theory

CMO 1. ACT-based skills in action.

Parents and teachers attending the intervention reported feeling that learning about ACT-based skills (*context*) enabled them to change how they viewed, and consequently how they managed stressful situations (*mechanisms*), leading to improved relationships with children, colleagues, as well as with themselves (*outcomes*).

Context

Parents and teachers commented that learning about ACT-based skills provided a basis to reflect on their behaviours, specifically in relation to the stressful situations they faced at home and at school:

“I think that you actually had to think about yourself, and just challenge yourself.. I think that did it and just think “Oh really, why do I this, why do I think this” and I found that very helpful.” (Teacher 1)

“I really enjoyed the ACT part of it, apart from- I don’t mean apart from week 1 but I was a bit wary of week 1 because I just wasn’t sure about it. But then the whole sort of sitting with your feelings, I wasn’t sure of that at all cos we’re just so used to being told don’t have negative feelings you just sort of get away from it but know it is so – it’s good in a way you can say right I’ve got these feelings it’s fine.” (Teacher 2)

Mechanisms

Following the intervention, teachers and parents reported adopting wider, ACT-informed viewpoints on the stressors they were facing:

*“I notice particularly that there can be - be things that *child’s name* will do that will just really wind me up. And you go from being completely understanding to just wanting to lose your patience. So instead of just - when I’m feeling like that I try to stand back and say I notice I’m feeling very irritated or whatever it was and I didn’t go down that whole spiral.” (Parent 3)*

Similarly, parents and teachers reported using ACT-based techniques taught at the intervention, including mindful practice; use of metaphors; experiential acceptance; and identifying realistic, meaningful goals, as is described in the following quote:

“The work is never done. So you’ve got to kind of draw a line and say, this is what will get done you know, and this is how I’ll do it, I’ll do really well and maybe the better part of the day maybe will just do somehow. And not everything has to be done to perfection.” (Teacher 1)

Outcomes

The use of ACT-based skills reportedly led to increased psychological wellbeing, and increased self-efficacy in managing both challenging behaviour, and challenging situations in general.

One teacher described having started to behave more in line with the valued aspects in their life, such as spending more time with family, as conducive to increased psychological wellbeing:

“I definitely, for example, you know how at the end of the group year we’re meant to give ourselves some kind of task to work on, so my task was to basically try to leave by 4 o’clock if possible, sometimes it’s not possible, but if possible. And it has made a big difference actually in my life.” (Teacher 6)

Another teacher recounted utilising the ACT-based skill of cognitive defusion to increase their efficacy in managing challenging behaviour:

I used the techniques at home because some of them are quite time consuming, but I think what I said earlier about right there’s a bad thought a negative thought, it’s there, it’s almost like that will get dealt with when I have my time. I mean I know you’re maybe regularly dealing with this behaviour or challenging behaviour, but then the negative feeling, putting that to the side, I felt made me able to deal with what was in front of me better.” (Teacher 1)

Similarly, through the use of self-as-context and present moment awareness techniques, some teachers commented that they felt more able to manage challenging situations at work, as exemplified below:

“I think because the ACT has helped me so much that I’m not as stressed, well I am still stressed, but em I just feel that because I’m able to manage myself a bit better I manage situations better, I-I’m more me, dealing with them so, ‘cos before I’ve taken

on other people's feelings and things. I feel like after I've dealt with a situation like that's not normally how I would have dealt with it but now I can just feel I can do my job the way I do my job and it's much better." (Teacher 2)

A diagrammatical representation of CMO 1 is presented below (Table 3).

CMO 2. PBS-based skills in action.

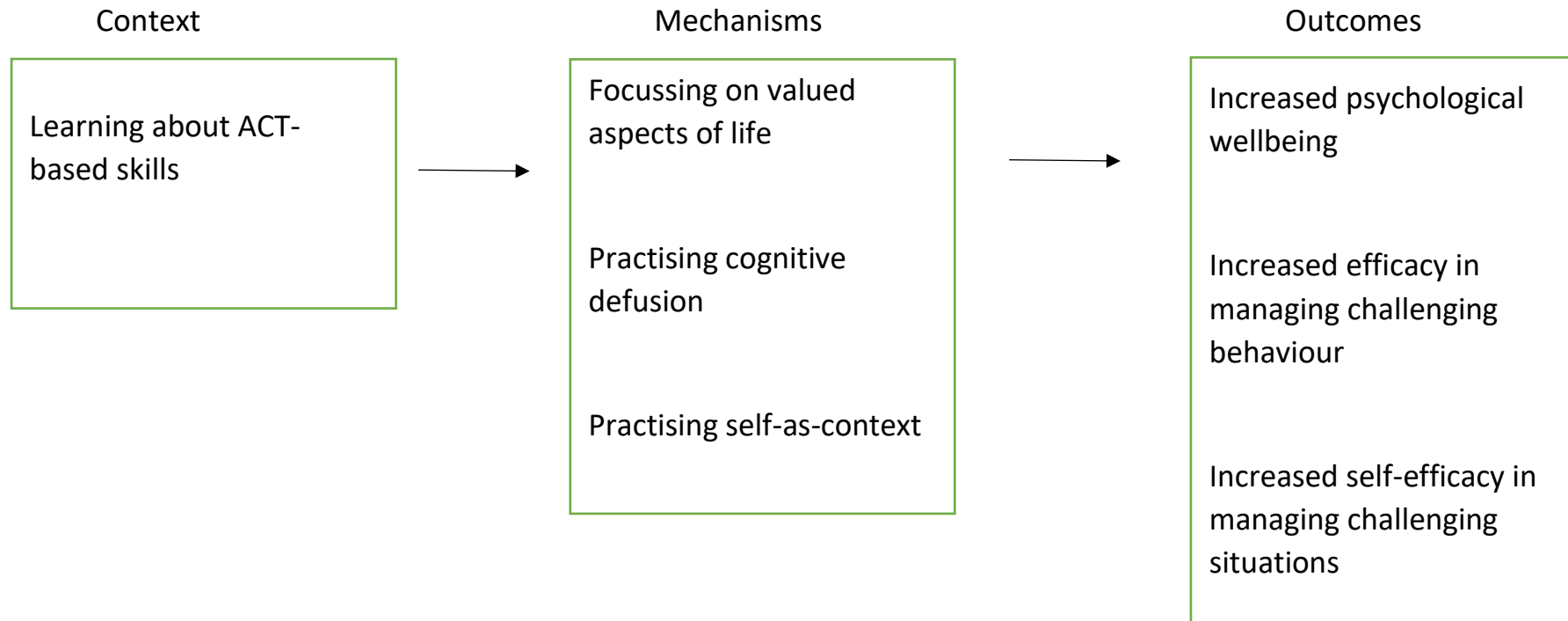
The second CMO configuration relates to learning about PBS skills (*context*), which was hypothesised to generate an increased understanding of the theory underpinning PBS, and consequently an increased appreciation that PBS plans require consistent implementation in order to function properly (*mechanisms*). The proposed *outcomes* of this configuration were: reduced psychological distress in parents and teachers, and increased consistency in implementing the PBS plans.

Context

The context of the second CMO configuration related to learning about the theory underpinning PBS. Parents and teachers commented that such learning enabled them to shift their view on nature and function of the children's challenging behaviour:

"I'm always just wanting to sort of get on top of what I'm doing, so, PBS is such a big thing right now so I just kind of wanted to learn a bit more about it." (Teacher 7)

Table 3. CMO 1. ACT-based skills in action.



Mechanisms

Interviewees shared that learning about PBS and its theory enabled them to acquire an increased appreciation of how to interpret the child's behaviour, and consequently how to set appropriate boundaries, as recounted by one parent:

*"Between the course and the input (*PBS intensive input received by family from CAMHS-ID*), definitely feeling more understanding of how I can feel in control, realising that (*child's name*) doesn't actually want to be in control, she might think she does but that she responds when we take charge." (Parent 2)*

*"Yeah, so obviously there's people in the house doing it (*CAMHS-ID PBS input*) and I've not really labelled the action with it so I got the gist that there was always a reason for the behaviour." (Parent 3)*

Teachers moreover commented that while they were mostly aware of PBS, the intervention allowed them to expand that knowledge:

"It extended our knowledge of PBS in a way." (Teacher 3)

Although not all teachers shared this sentiment:

"I feel like I didn't get much out of the PBS part." (Teacher 1)

"Could have done more on the PBS side..." (Teacher 8)

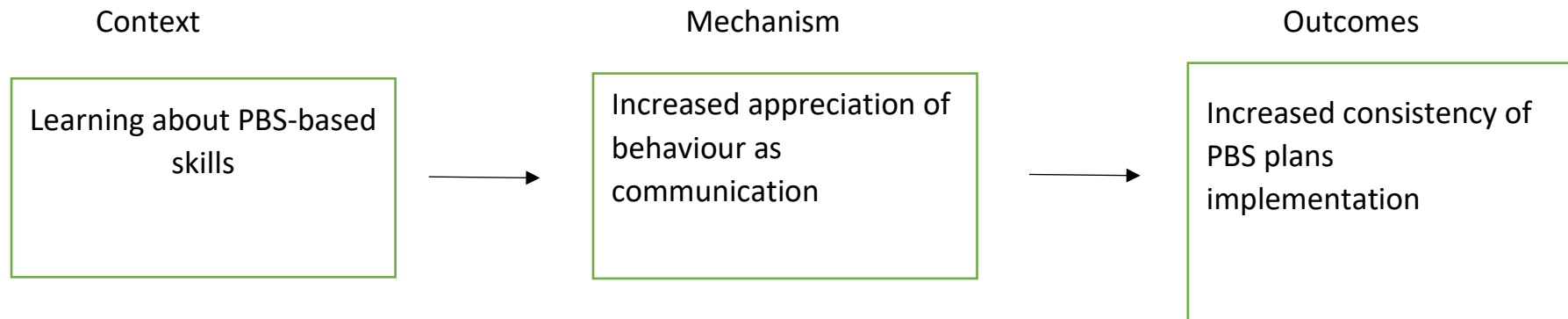
Outcomes

Parents and teachers commented that learning about, or expanding their knowledge of PBS, led to a decrease in their psychological distress, and to an increased appreciation of the need to implement PBS plans consistently, including through communicating this need to other members of the child's system, as recounted by one of the parents:

“When you’ve got a 5, 6, 10-year-old, 16 year old, then you think that you know ((laughs)) but you have to keep reminding yourself, or with me it’s reminding the other people in the family, in the household, look he’s chucking something, let’s just get out of the way, it could be he might need space he might be tired, he says ‘I’m hangry’ ‘I need peanuts’ and you know it’s understanding all the little nuances of their behaviour. (Parent 4)

A diagrammatical representation of CMO 2 is presented below (Table 4).

Table 4. CMO 2. PBS-based skills in action.



CMO 3. Learning and sharing in a group of peers.

The third and final CMO configuration of the IPT hypothesised that participating in the intervention in a group of peers (*context*) resulted in increased social support, as well as in an understanding that other teachers and parents also experience negative self-attributions (*mechanisms*). Consequently, parents and teachers felt they experienced a decrease in psychological distress on the one hand, and an increased motivation to attend the intervention on the other hand (*outcomes*).

Context

The structure of the intervention followed a group format, which was well received by both parents and teachers. One teacher in particular lamented that they felt isolated in their work, and welcomed the opportunity to share views and learn new techniques with fellow colleagues:

“I think not only until you put everybody in the same room it still feels very isolating”.

(Teacher 1)

Similarly, another teacher commented that they enjoyed being exposed to the narratives of their colleagues:

“Really unique and sort of part of education, so it was nice to hear other people’s experiences and feedback, so it was really relevant.” (Teacher 5)

Mechanisms

The group format of the intervention generated a sense of understanding and support between the participants. Moreover, it created a safe space for sharing distressing emotions, as exemplified by two parents:

“We’re going through similar situations, and it was really nice to actually be with people who weren’t being judgmental.” (Parent 2)

“...we’re so used to going into situations where we’re being judged, or our children are being judged or you know whatever that it was really positive to eh come into a group where that just wasn’t an issue.” (Parent 2)

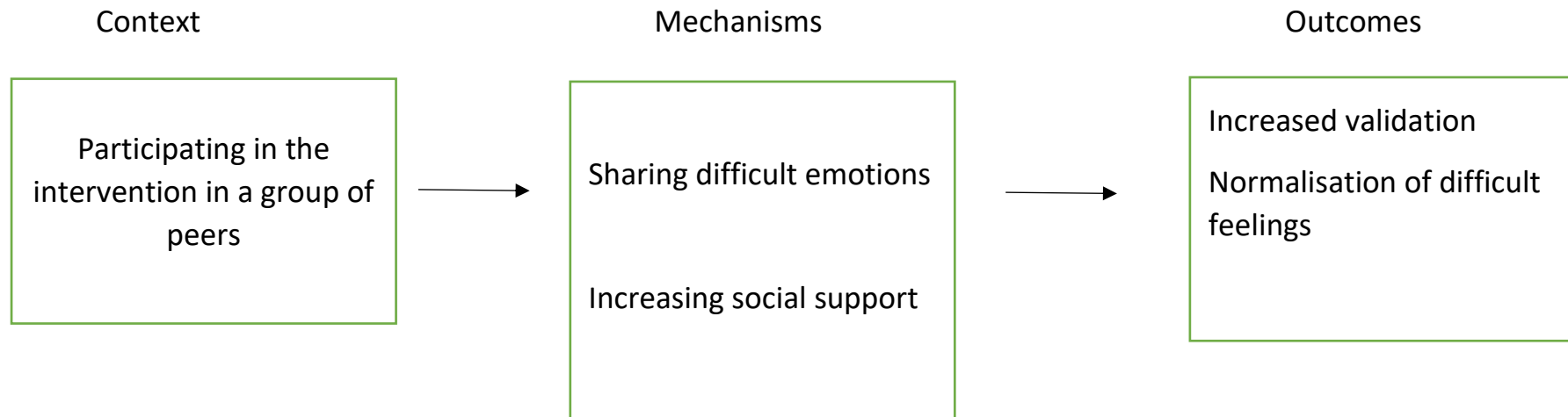
Outcomes

The primary outcome of sharing distressing emotions with peers, and learning new skills in a group format, was that of increased validation and normalisation of difficult feelings, as described by one of the parents:

“Yeah like I think I was the same as everybody else, ehm I had just been going through a really stressful phase which you do, and just felt validated by the group, you know actually you’re entitled to have negative feelings and that it’s not just you”.
(Parent 5)

A diagrammatical representation of CMO 3 is presented below (Table 5).

Table 5. CMO 3. Learning and sharing in a group of peers.



CMO 4. Blending ACT and PBS principles.

Interviewed experts commented that it may not be sufficient to teach ACT and PBS skills as separate entities to achieve the outcomes of reduced personal-related burnout, and increased consistency in PBS plan implementation (discrepancies ii and iii). Instead, experts suggested that a truly combined ACT and PBS intervention should try to use elements of ACT in how PBS is presented (*context*), leading to increased psychological flexibility in carers through a process of “seeing PBS through an ACT lens” (*mechanism*). This is hypothesised to pave the way for a reduction in personal-related burnout and increased consistency in PBS plan implementation, as well as for increased positive interactions with children, and decreased psychological distress (*outcomes*).

Context

Experts suggested that ACT and PBS should not be viewed, and taught, as separate entities. Using contextual behaviour science (CBS) as a framework for understanding the quantitative and qualitative data presented to them at the interview, they proposed that the optimal basis, or context, from which outcomes such as decreased psychological distress in carers, and increased efficacy in managing challenging behaviour emerge, require carers to think of interventions such as ACT as a basis to learn how and when to use PBS skills effectively, as is described by following extract:

*“I think the ACT world, or – it is probably best to talk about the contextual behaviour science world, offers a richer way of understanding the full range of influences on human beings. We’re not the same as animals, we’re complex verbal creatures. We will come under the control of environments, there are operant forces independent of our verbal account that just happens. So, I actually think we’ve got to get away from seeing them (*ACT and PBS*) as separate, we got to understand the history, the ideas, within a broader, behavioural-science perspective.” (Expert 5)*

Mechanisms

Interviews with experts highlighted that, in order for the intervention to be successful in achieving all of the desired outcomes, participants should be taught PBS-based skills from an ACT point of view. The combined intervention should thus blend together elements of ACT and PBS, so that PBS becomes a skill that is driven by ACT-based concepts such as choice points and value-oriented behaviour, as exemplified by the following quotation:

“So from that point of view, implementing a PBS strategy can become a value, can become a valued action. So then my ability to do that, I’m being the kind of caregiver I want to be, I want to implement this PBS strategy. So from that point of view, you can think of it as actually that the – the language of PBS and what PBS is doing it’s utilitarian, it’s useful, it’s pragmatic, and you could in many ways simply dissolve the PBS and seeing that everything you’re doing is ACT.” (Expert 2)

Outcomes

By using ACT to provide a contextual-behavioural basis to the teaching of PBS, outcomes such as decreased psychological distress, increased efficacy and consistency in PBS plan implementation, and decreased personal-related burnout, would all be expected to emerge. Ultimately, the goal of a combined ACT and PBS intervention becomes to increase the quality of life of the child and of the carer, with all remaining positive outcomes unfolding naturally, as summarised by one interviewee:

“There’s a lot of people taking ACT into their behaviour interventions now, and PBS is probably given us a richer framework. The whole idea around working with stakeholders, of having quality of life as the end-product means you look at a different horizon, we’re not there at eradicating behavioural challenges, and then increasing a few skills. It’s about somebody having a life of real meaning. And that brings us in contact with the concept of values.” (Expert 3)

Furthermore, one expert suggested that a combined ACT and PBS intervention may equip participants with a novel understanding of the children’s challenging behaviour, leading to a change in the relationship between carer and child, and consequently to a reduced need to implement PBS plans altogether:

“...staff became so much more aware of their own behaviours that there definitely was a change in how they interacted with individuals and did not feel the need to follow their PBS, ‘cause their relationship with their clients changed, cause in fact, they interacted with them different, and that again caused behaviour changes in the client.” (Expert 6)

A diagrammatical representation of CMO 4 is presented below (Table 6).

CMO 5. Learning and sharing in a group of peers.

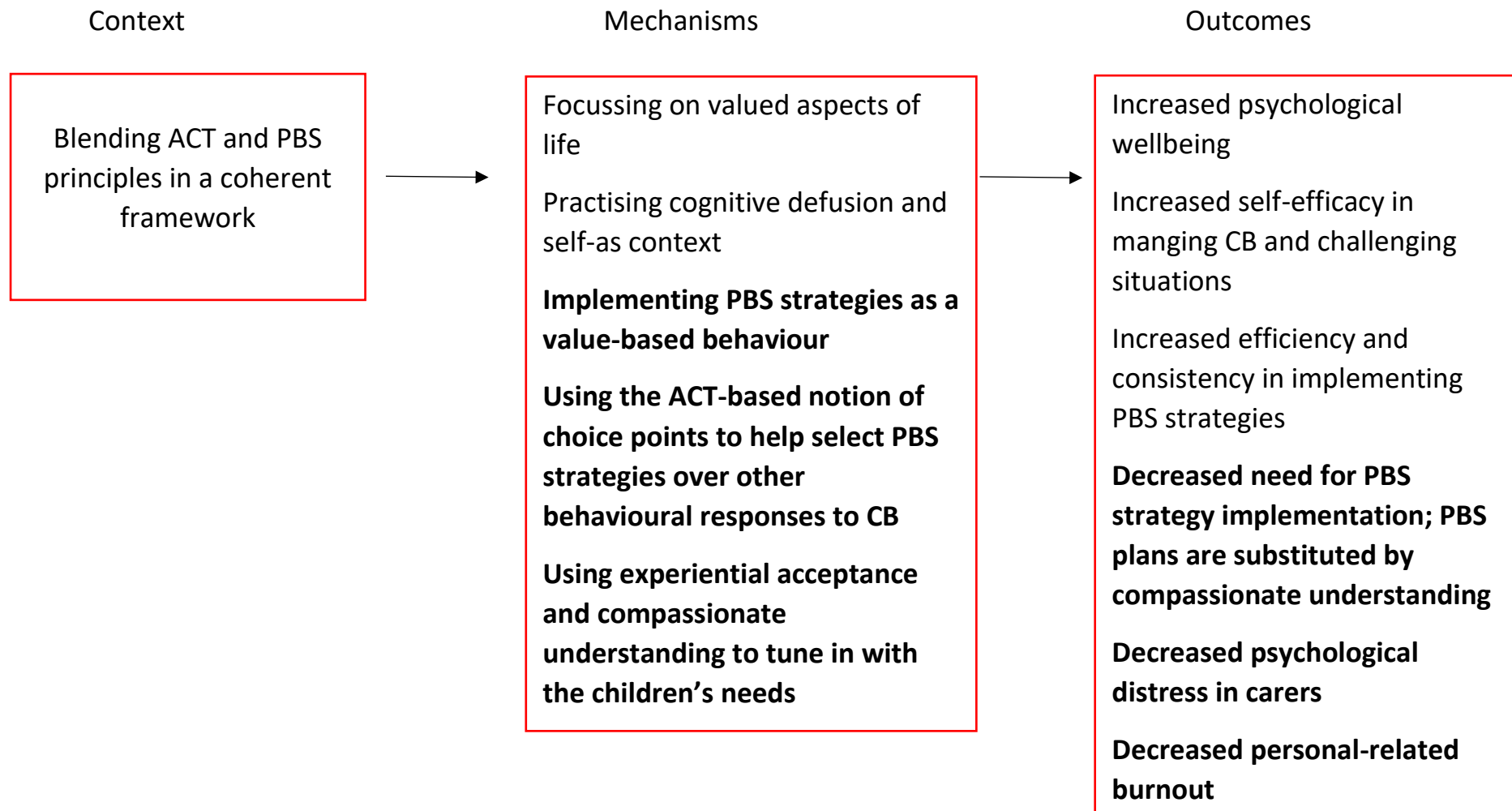
Interviews with experts led to a refinement of IPT's CMO 3, specifically in relation to the *context* of learning in a group of peers, where the use of a shared language was highlighted as conducive to a behaviourally reinforcing environment. Behavioural reinforcement through shared language was described as a means to achieve consistency in PBS plan implementation, as well as increased self-efficacy in managing challenging behaviour (*outcomes*). Secondly, further to the mechanisms of normalisation of negative self-attributions, and increased social support, it was suggested that learning about ACT skills would lead to an increased understanding of the challenges that colleagues and fellow carers experience (*mechanism*).

Contexts

Further to learning new skills and sharing difficult feelings in a group format, working in synergy with fellow carers appears to be also dependent on the creation of a shared vocabulary, as suggested by one expert:

“When I did my staff team group work, we found that if you had people from the same service or the same department or same ward, if they’ve been through it, then suddenly they have a shared vocabulary now.” (Expert 5)

Table 6. CMO 4. Blending ACT and PBS principles.



Note: elements in **bold** denote new additions to the CMO configuration.

Mechanisms

In addition to the two mechanisms included in CMO 3, it was suggested that the use of a shared vocabulary would lead to an increase in the practice of some ACT-based skills:

“You know, this isn’t just, I’m furious at that client, that child, that patient, now it is, ah, a passenger just showed up. And then you get reinforcement around that, and it removes some of the stigma around talking about bad things that show up.”

(Expert 5)

Interestingly, one expert suggested that, in their experience, the absence of a shared vocabulary can lead to negative reinforcement, and subsequently to the extinction of the skills learned through the intervention:

*“If they go back into the workplace, or the school, or the department, around people who haven’t been through that (*intervention*), then you run into contact with quite possibly punishing contingencies. People who just aren’t on the same page, or a skeptical, or disagree with it, or whatever. It’s hard to maintain a behaviour in the face of constant punishment schedules.” (Expert 6)*

Outcomes

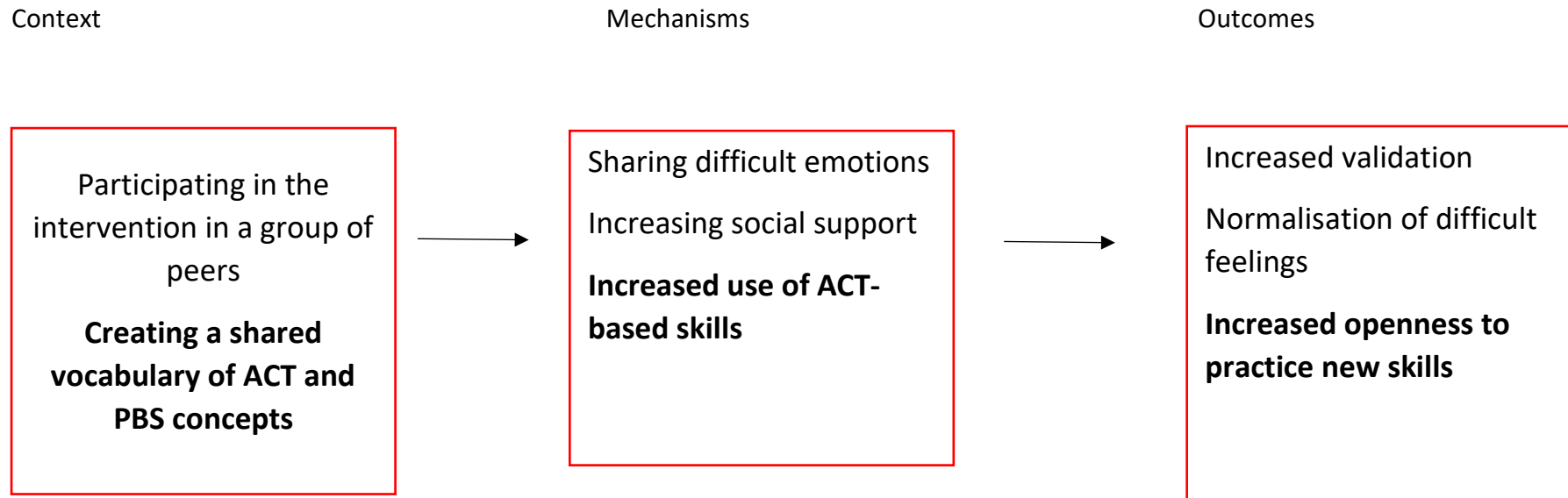
The outcomes of CMO 5 are the same as those delineated in CMO 3, with one addition. Experts agreed that a context of shared learning and shared vocabulary would activate the mechanisms of social support, normalisation of negative self-attributions, and the promotion of positive reinforcement, helping carers manage difficult emotions more effectively.

Moreover, a shared vocabulary was hypothesised to increase the carers' openness to practising new skills, as described by one interviewee:

“Behaviour goes where reinforcement flows. So, you know, it doesn't surprise me at all that people felt more comfortable engaging in mindfulness activities, talking about mindfulness activities, using the words like, I'm noticing right now that I'm feeling really uncomfortable, or, I'm just going to take a couple of deep breaths here before I answer. If I train my practitioners in ACT, I would use that language all the time.”
(Expert 4)

A diagrammatical representation of CMO 5 is presented below (Table 7).

Table 7. CMO 5. Learning and sharing in a group of peers.



Note: elements in **bold** denote new additions to the CMO configuration.

CMO 6. Operating in a supportive environment.

Following interviews with experts, it appeared that, in order to achieve the desired *outcomes* of: consistent implementation of PBS strategies; increased self-efficacy in managing challenging behaviour; decreased psychological distress in carers; and decreased work-related burnout, carers need to operate in an environment that is supportive of the changes that the intervention introduces (*context*). Only through such an adjustment to the environment a lasting shift in environmental contingencies becomes possible, specifically, through support from senior colleagues, and through the modification of daily routines to accommodate the necessary practice of newly acquired ACT and PBS skills (*mechanisms*).

Context

Two experts commented that the acquisition of knowledge is often an insufficient driver for behaviour change:

“From a Contextual behaviour science perspective, knowledge might be thought of as being a relatively weak driver of behaviour relative to context, and so I would – I mean knowledge is part of the context, and you know, how you perceive the context is shaped through your knowledge, but I would say that the logical explanation here is that knowledge is not a strong driver.” (Expert 1)

“...it’s a big issue with behaviourally-based interventions, it’s to do with the effectiveness, the efficacy of teaching. Having uhm teaching sessions, predominantly didactic, we know that doesn’t bring about behavioural change – actually behaviour change comes about by altering environmental contingencies and that’s as much for teachers.” (Expert 6)

Interviews with experts moreover highlighted that lasting behaviour change is instead achieved through the creation of a nurturing, well-resourced and well-structured environment within which the carer operates, as exemplified by the following quotations:

“I think that an ACT framework could help, but I think what you want is, in truly CBS fashion, to not think about that as being, we’re going to alter the individual’s openness, awareness and engagement, what we’re going to do is use our understanding to create a really nurturing environment, and adequately resourced.”

(Expert 1)

“One implication of that is that models and pathways to do this kind of work need to build into them the idea of ongoing maintenance ... I think that we need to recognise that the environment the person is probably back in when they’re back at school, back a home, isn’t naturally sustaining this kind of open, aware, engaged ehm mindset, so what we probably want to do is a couple of things. One is to have explicit environmental strategies that support psychological flexibility, choosing different kinds of ways to sort of cueing people in this kind of mindset ... Second thing could be building in practises of like daily check-ins or team reviews.” (Expert 6)

Mechanisms

Shaping the environment to support carers to achieve lasting change translates into direct support from the employer in implementing ACT-based principles in the teachers’ workplace, including involving senior colleagues.

“There’s a big, big literature on the effectiveness of behaviourally-based interventions, of getting care staff to do stuff, and actually, procedural integrity is more likely to be improved if you have ongoing supervision, if you have people that actually model – so they tell you what they want you to do, they show you, they give you the chance to do it, and then they give you feedback, a core behavioural skills training. (...) I’m trying to think of something similar, I’ve not done this in schools yet, but you know, having someone within the organisation who is trained at a very high level who takes a leadership role, then an intermediate level, a person who can offer regular supervision.” (Expert 5)

As for parents, and unpaid carers in general, experts suggested that it would be helpful to modify some of their daily routines, to accommodate the practice of ACT and PBS skills regularly, as one expert suggested in relation to the practice of present-moment awareness:

“We know that if you meditate regularly, you experience massive changes, yeah but, you have to do it regularly. So, helping people to find the time, a naturally occurring habit that they can latch onto, so it might be that there’s a particular time of day where they can just be still. That there’s a routine in their day for 10 minutes where they can latch on and practice. That increases the likelihood that the new behaviour patterns will be integrated with the old ones.” (Expert 4)

Outcomes

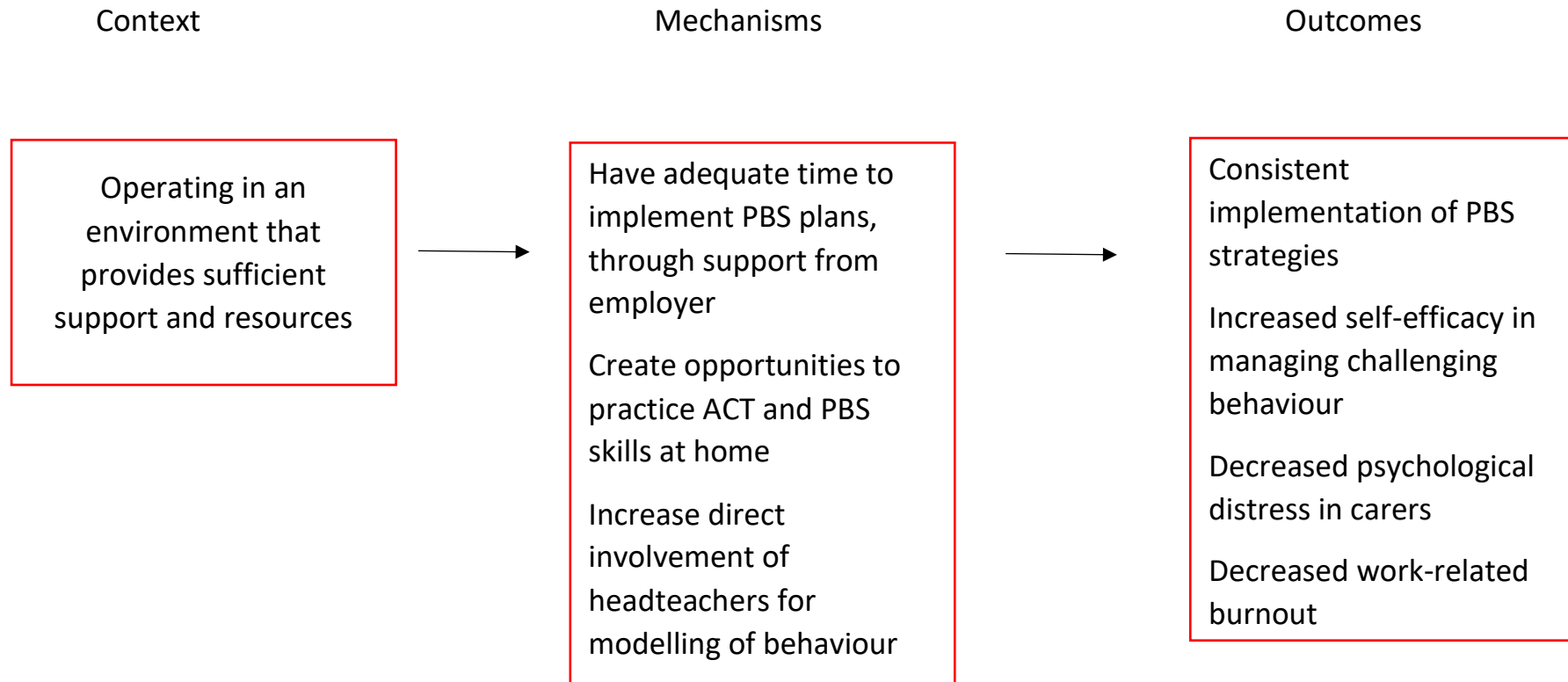
Ultimately, receiving support from senior colleagues, and making space for practicing new skills in your day-to-day life, was described as a necessary precursor to

achieving a consistent implementation of PBS strategies, and a decrease in psychological distress in carers, particularly distress linked to the workplace. One expert shared the following experience:

“Most of my work has been with staff. And teaching ACT with staff and having behaviour analyst use ACT in their lives and become better interventionists, and really finding value in their work. And I can tell you from a staff perspective, it’s been pretty amazing to see real transformation, really good transformation as it relates to how they view their work, the stress of their work, how they deal with their employees, how they have increased their confidence as a clinician, how they’ve been kinder and more compassionate to themselves as clinicians.” (Expert 5)

A diagrammatical representation of CMO 6 is presented below (Table 8).

Table 8. CMO 6. Operating in a supportive environment.



Discussion

Interpretation of study results

Before presenting a detailed interpretation of the study results, it is worth briefly noting the complex process of generating CMO configurations. First, as qualitative data emerged from each of the two sets of interviews, it became apparent that a concise and unidimensional presentation of all analysed data was not possible, due to the variety of topics discussed with both carers and experts. As observed by other researchers (e.g., Byng, Norman & Redfern, 2005), a heterogeneous pool of qualitative data is hardly conducive to a single mechanism - context – outcome series of configurations, as was originally proposed by Pawson and Tilley (1997). To accommodate such heterogeneity, each configuration generated in the present study includes multiple contexts, mechanisms and outcomes. Secondly, as the present study followed the guiding principle of constructing CMOs in a theory-driven manner, only those interview extracts that built on existing theories on how ACT and PBS interventions operate in relation to the research question were selected to construct the CMOs, while others that did not were excluded. For instance, extracts that discussed individually tailored versions of the intervention, as opposed to its current group format, were not included, although this would seem an interesting area of exploration. This process of data exclusion is aligned with the concept of “intellectual independence” (Riessman, 1993), which postulates that it is the researcher who, on the basis of their methodology, decides which portions of data are to be included in the final analysis.

In terms of results interpretation, the middle-range programme theory (MRPT) highlighted the need for complementarity between the ACT and PBS elements of the intervention. Although experts did not provide exact indications on how the two interventions could be merged, they suggested that a truly combined ACT and PBS intervention should aim to infuse PBS skills with the ACT and contextual behavioural science models of behaviour modification and psychological flexibility. By merging ACT and PBS in such manner, the MRPT postulates that the elusive outcomes of decreased carer personal-related burnout, and consistent PBS plan implementation, may be achieved. This is an interesting avenue of exploration, as currently not much is known about how such merged interventions compare with other versions.

Moreover, the MRPT postulates that in order to achieve a lasting behavioural change in how a child is cared for, carers should aim to adopt a shared vocabulary of ACT and PBS concepts. For example, one expert suggested that in their experience, carers modelling the use of the ACT “passengers on the bus” metaphor as a means to share distress with colleagues improved their access social support, as the use of the shared vocabulary helped carers overcome the obstacle of expressing difficult emotions. Furthermore, experts highlighted the benefits of extending the shared vocabulary with their wider professional network, or likewise with family members who do not provide direct care to the child. The ramifications of such a result are important, as the utility of introducing a shared vocabulary points towards the benefits of homogenising the whole system around the child, not just those persons that are directly involved in their care. Thirdly, CMO 6 highlighted the need to create a context, be it within a professional or home environment, that supports and maintains behaviour change in carers. Specifically, interviews with both carers and experts highlighted that providing care to children with intellectual disabilities in an

environment that is not open to realigning its structure with ACT and PBS-based principles is less likely to achieve sustained behavioural change and new skill implementation in the medium and long terms. It should thus come as no surprise that quantitative data on self-efficacy in managing challenging behaviour indicated a return to baseline 6 weeks after the intervention ended in Connolly's study (2020). Such a view on behaviour change is a critical addition to the programme theory of the combined ACT and PBS intervention, as a majority of discrepancies identified at MRPT level were directly linked to difficulties in maintaining gains over time, as well as in difficulties in practicing PBS and ACT skills consistently within the constraints of a demanding work and family life.

Strengths

The present study has several strengths. Firstly, the meticulous methods of data collection inherent to realist evaluation allowed for a rich understanding of which contexts and mechanisms were conducive to the desired outcomes. This in turn provided valuable indications on how such interventions can be adapted to different settings, and which future studies should endeavour to examine. Secondly, generating qualitative data from three different sets of stakeholders, namely, parents, teachers, and experts, enabled a cross-examination of the subjective experiences with the theoretical understanding of the intervention. Lastly, the results of the study provide valuable insights into how future pilots of combined ACT and PBS interventions should be structured, facilitated, and evaluated to achieve the desired outcomes, and maintain such achievements over prolonged periods of time.

Limitations

In order to appropriately contextualise the findings of the present study, a number of limitations need to be considered.

Firstly, it was not possible to follow the realist evaluation paradigm of IPT and MRPT construction at all levels, as the interviews conducted by Connolly (2020), which provided some of the bases for the IPT, did not ask the study participants to comment directly on CMOs 1, 2, and 3 in their interviews, and invited them instead to share their experience of the intervention.

Secondly, interviews with experts were limited to six participants, knowledgeable in the fields of intellectual disabilities, ACT, and or PBS. The first limitation pertinent to this area relates to the relatively low number of interviewees, while the second relates to the fact that almost all interviewees described themselves as behaviourists, and consequently approached the questions posed at the interview from a strictly behavioural viewpoint. Arguably, a greater number of experts would likely have increased the heterogeneity of theoretical backgrounds, in turn enriching the pool of *contexts* and *mechanisms*.

Thirdly, the present study relied on two different formats of interviews; specifically, the first set of interviews with participants employed a group design, while the second set of interviews conducted with experts was undertaken on an individual basis. Indeed, the analysis of each set of interviews highlighted a marked difference in how the questions were answered, with group interviews often including instances of disagreement between interviewees, which was conducive to useful elucidations within the interviews themselves. Conversely, disagreements between the individual

interviewees in the second set of interviews could only be analysed and codified by the author in a post hoc fashion.

Finally, it is worth noting that an issue of contention when using realist evaluation methods resides in the difficult endeavour of resolving discrepancies between different sets of interviews, that is, discrepancies between participant interviews and expert interviews. As the realist evaluation approach does not provide the researcher with a fixed set of methodological steps, it also does not include a precise indication on how to resolve such discrepancies (Fick & Muhajarine, 2019). In the present study, no attempt was made to resolve the discrepancies; instead, all views were considered as equally valid and included accordingly.

Clinical implications and future directions

The present study adds considerably to the literature pertaining to combined ACT and PBS interventions for carers of children with intellectual disabilities, namely, by identifying and describing the contexts and mechanisms necessary to achieve the desired outcomes of such interventions. On the basis of the results codified in CMOs 4, 5, and 6, the present study posits that, in order to maintain behavioural change in carers after the intervention has ended, carers should aim to adopt a shared vocabulary. In addition, the working and living environments of carers should themselves be aligned with the theories of behaviour change inherent to ACT. This can be fostered by allowing superiors in the workplace to be also exposed to the intervention; in this manner, teachers who attend the intervention can subsequently be supported in fostering their newly-acquired skills through a system of supervision and behaviour modelling from superiors, and receive protected time to practice the

implementation of new skills. The working environment itself should moreover be carefully constructed to allow staff to address issues of challenging behaviour with a more proactive stance; that is, time and resources should be allocated to enable staff to analyse the behaviour, and subsequently compile, implement, and review relevant PBS strategies.

Family members who are not directly involved in the care of children should also be made aware of the tenants of ACT and PBS, to increase their appreciation around lasting behaviour change. Therefore, combined ACT and PBS interventions should be aimed at the whole system of persons linked to the child.

Results furthermore suggest that special education needs schools would likely benefit from ongoing consultancy, ideally from the same team who facilitates the intervention, on how the workplace culture can adopt ACT and PBS-based principles.

Finally, due consideration on refresher sessions and regular full-day retreats should be given, to allow carers to cement their learning over time; reflect on any changes they might have noticed, both in terms of psychological wellbeing, and perceived efficacy in caring for the child; and identify additional training needs.

In terms of future directions for research, the next step in theory refinement would entail adapting the original intervention (Connolly, 2020) from teaching ACT and PBS skills separately, to teaching these in a merged format, as per the results presented in CMO 4. Such an adapted intervention should then be tested through new sets of qualitative and quantitative data, and new MRPTs should be compiled as required. A pilot study using a longitudinal design would benefit from moderation and mediation

analysis, as well as from a repeated measures ANOVA for their quantitative assessment. From a qualitative perspective, a newly devised pilot would benefit from interviews focussed on eliciting the intervention participants' views on the interventions' theoretical tenants, or programme theories in realist evaluation speak. Similarly, experts on merged formats of behaviourally-based and third-wave interventions should also be interviewed.

In terms of the quantitative measurements employed in Connolly's (2020) pilot study, interviews with experts indicated that careful consideration should be given to the measurement and analysis of baseline burnout in carers, as statistically significant changes to levels of burnout in carers can be generated by a small pool of participants who experience markedly high levels of burnout, and greatly improve on this dimension following the intervention (i.e., statistical outliers). As described in an influential document on the quality and reporting standards of realist evaluation (Wong et al., 2017), "excellent" methodologies should aim to employ new methods of data collection and analysis whenever the need arises. Therefore, it is recommended that future research includes analyses of subgroups of participants on the measure of burnout, as well as post hoc analyses, to optimise the validity of results on this measure.

Similarly, future pilots of the intervention should aim to measure the impact of refresher sessions, both qualitatively and quantitatively, should these be added to the intervention protocol. In addition, it would be useful to determine whether improvements in levels of psychological wellbeing in carers and children can be maintained over extended periods of time, particularly in those carers who continue to experience the same amount of environmental stressors, as such a result would corroborate the utility of ACT-based interventions for those carers who cannot exert

influence on their stressors. Equally, psychological wellbeing and levels of stress should be measured in participants who are exposed to positive changes to their working and living environments, and compared with carers whose environments remain unaltered, to determine the impact of changes to the environment on the carers' psychological wellbeing.

Finally, future studies should aim to determine the impact of incorporating regular practice sessions, and protected time for skills implementation and supervision, on the perceived efficacy of carers in caring for the child, as well as on their own and the child's psychological wellbeing. Given that sustained behavioural change often emerges past the typical 6 to 12 weeks follow-up measurements, it is recommended that longer, regular follow-up periods are established.

Conclusion

The present study built on a piloted combined ACT and PBS intervention (Connolly, 2020), by examining which elements of the intervention work for whom, and under which circumstances. This was achieved through the compilation of an initial programme theory of the intervention, tested with a mixed methodology, and subsequently refined in the form of a middle-range programme theory. The middle-range programme theory posits that, in order to decrease the psychological distress of carers of children with intellectual disabilities, increase carers' psychological flexibility, and increase carers' perceived efficacy in caring for the child, the intervention should merge elements of ACT and PBS in a unitary format. Furthermore, in order to sustain desired outcomes over time, consideration should be given to offering refresher sessions; offering the intervention to all persons

included in the child's system; and to offering ongoing training and consultation to workplace environments so that these may support the practice and implementation of newly acquired skills; in short, it recommends that carers operate in adequately resourced environments. Lastly, it is hypothesised that facilitating the intervention in a group format would help carers manage their difficult emotions, feel validated, and increase their openness to trying new skills through the mechanisms of increased social support and use of a shared language.

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Appendices

Appendix A. Ethical approval for Data A



SCHOOL of HEALTH IN SOCIAL SCIENCE

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26 November 2020

Dear Matteo Turco de Pretis-Cagnodo,

Application for Ethical Approval

Reference: CLIN795

Project Title: Refining a group ACT & PBS intervention for parents and teaching staff of children with IDs: a realist evaluation

Thank you for submitting the above research project for review by the School of Health in Social Science Research Ethics Committee (REC). I can confirm that the submission has been independently reviewed and was approved on 30th July 2020.

The standard conditions of this approval are:

- I. Conduct the project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments made to the proposal required by the REC.
- II. Advise the REC (by email to ethics.hiss@ed.ac.uk) of any complaints or other issues in relation to the project which may warrant review of the ethical approval of the project.
- III. Make submission for approval of amendments to the approved project before

implementing such changes.

IV. Advise in writing if the project has been discontinued.

The School's Research Ethics Policy and further information and resources are available on the School's website.

You may now commence your project; we wish you the best of

luck. Yours sincerely,

Sanni Ahonen
Administrative
Secretary
School of Health in Social Science

Appendix B. Ethical approval for Data B

CONCLUSION TO ETHICAL REVIEW (if required)

The applicant's response to our request for further clarification or amendments has now satisfied the requirements for ethical practice and the application has therefore been approved.

Signature:

Position: Ethics and Integrity Lead/Lecturer in Applied Psychology

Date: 1.4.21

Appendix C. List of questions, first set of interviews, teachers and parents

Please answer the following questions as best as you can.

What were the most helpful parts of the workshop?

What were the least helpful parts of the workshop?

What were the barriers (if any) to practicing the techniques from the workshop?

Is there anything else you would like to add?

**Thank you for your time in
completing these questionnaires!**

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***Note:** Questions were discussed with participants in a spoken interview format.

Appendix D. List of questions, second set of interviews, experts

Number	Questions	Aim
<p>1 (15 minutes)</p>	<p>Interviews with teachers highlighted a perceived increase in self-efficacy in managing challenging behaviour (CB), specifically through the following ACT components of the intervention:</p> <ul style="list-style-type: none"> - Having a wider perspective - Having an increased appreciation of colleagues' feelings and behaviours - Committing to adhering to work timetable, which in turn allowed teachers to invest more time in valued areas of life, e.g. spending time with family. <p>In contrast to the perceived increase in self-efficacy, quantitative data suggests that such increase was not maintained at 6-week follow-up.</p> <p>The theory suggests that the increase in self-efficacy should be maintained at follow-up.</p> <p>[might depend on how much you practice mindfulness between sessions + after intervention has ended]</p> <p>1.1 - How do you make sense of such result?</p> <p>1.2 - How may the programme theory be modified, if the increase in self-efficacy in managing CB was to be maintained over a prolonged period of time?</p>	<p>Exploring discrepancy between perceived increase in self-efficacy in managing CB, and quantitative data not supporting this at 6-week follow-up.</p>
<p>2 (10 minutes)</p>	<p>Teachers reported increased job satisfaction, following an increased appreciation that not everything needs to be fixed. However, quantitative results indicate that there was no significant reduction of work-related or person-related burnout, only of client-related burnout (as measured by the Copenhagen Burnout Inventory).</p> <p>The theory behind the intervention, as it stands, suggests that all three dimensions of burnout (personal, work-related, and client-related) should decrease.</p> <p>2.1 – How do you make sense of this?</p>	<p>Exploring discrepancy between reported increased job satisfaction, and no reduction in work-related burnout.</p>

	<p>2.2 – Is it correct to assume that job satisfaction relates to decreased work-related burnout?</p>	
<p>3 (10 minutes)</p>	<p>Some teachers reported that, following the intervention, PBS plans were more efficiently implemented in collaboration with colleagues that were like-minded, specifically those who appreciated the need to implement PBS plans consistently.</p> <p>The theory, as it stands, suggests that the intervention should help carers implement PBS interventions more consistently. This appears to have been the case for parents, but not teachers.</p> <p>This begs the question:</p> <p>3.1 – How might the programme theory account for seemingly having failed to shift the teachers’ attitudes regarding the need to implement PBS plans consistently?</p> <p>Of interest, parents reported that through an increased appreciation of PBS’ rationale, they felt they were able to implement PBS plans more consistently. (<i>Parents CMO #4</i>)</p>	<p>Exploring issue around different teachers implementing PBS plans with varying degrees of consistency.</p>
<p>4 (10 minutes)</p>	<p>Both teachers and parents commented that they worked better in the intervention when peers took mindfulness seriously, as opposed to ridiculing it/not engaging with practice. They moreover commented that when attending the intervention with peers who also took mindfulness seriously, they were more likely to continue attending the intervention.</p> <p>The theory suggests that the intervention should normalize difficult feelings, increase participants’ understanding of mindfulness, and provide social support. However, this was true only for participants who were open to the concept of mindfulness prior to the start of the intervention.</p> <p>4.1 – How can the programme theory account for this?</p> <p>4.2. - How may one differentiate between participants who may take mindfulness seriously, and those who may not? Should this be explored during the recruitment phase?</p>	<p>Optimising group members’ cohesion.</p>

<p>5 (10 minutes)</p>	<p>The theory suggests that a combined ACT and PBS intervention leads to increased ability to manage emotions in carers, and to manage challenging behavior in PWDD. The theory moreover suggests that the two interventions are complementary, as the better one is at managing emotions, the more efficient they are at implementing CB management strategies. ["Seeing PBS from and ACT perspective"].</p> <p>5.2 – What is your view about MBIs complementing ABAs, in carers of PWDD?</p> <p>5.3 - What is your experience/What would you expect to see following an intervention that combines ACT and PBS?</p> <ul style="list-style-type: none"> - in terms of carer psychological wellbeing; and - in terms of PWDD psychological wellbeing 	<p>Mediating effect of ACT training on PBS implementation</p>
<p>6 (5 minutes)</p>	<p>6 - Is there anything else that you would like to share or discuss?</p>	<p>Elicit discussion around programme theory refinement.</p>