Evaluating the feasibility, acceptability and effectiveness of acceptance and commitment therapy for family carers of adults with intellectual disabilities

Gemma Shoesmith

A thesis submitted for the degree of Doctorate in Clinical Psychology

School of Health & Social Care
University of Essex

Submission date: March 2024

Acknowledgements

First and foremost, I would like to thank the family carers who participated in this study. This thesis would not have been possible without you.

I would like to say a huge thank you to my thesis supervisors, Dr Alison Spencer and Dr Nestor Asiamah. Thank you for guiding me throughout this process and supporting me every step of the way.

To my first psychology teacher, Mrs Williamson, thank you for helping me to fall in love with psychology and for supporting me through a difficult period in my life.

I would like to thank my previous supervisors. My work continues to be shaped by your guidance and encouragement.

To my mum, thank you for taking the time to proofread my thesis and for always telling me that I could do anything I set my mind to. Thank you also to Steph for providing the best baked goods to keep me going, for reminding me to take breaks and for checking in on me.

I would also like to say thank you to my friends on the 2021 cohort. I know I have made some friends for life. Thank you also to my friends outside of the course. Thanks for reminding me to take time away from my thesis and have fun.

I would like to say a special thank you to my partner, Lauren. What a journey we have been on to get here together. Thank you for your continued patience and emotional support over the last three years. You have encouraged and challenged me to be the best version of myself, and have always believed in me. I look forward to creating a life-time of memories together.

Finally, this thesis is dedicated to my Auntie Jan who sadly passed away last year. Thank you for always making me smile, and for showing me what people with learning disabilities can achieve and the blessings they can bring to your life. I will forever cherish the memories I shared with you, Nan and Chris.

Table of Contents

Abstract 6
Chapter One: Introduction 7
- Chapter Overview 7
- Background 7
- Impacts of Family Caregiving 7
- Criticisms of Family Research and Carer Involvement Policies 13
- Determinants of Parental Stress 14
- Interventions for Family Carers of Individuals with IDs 14
- Methodological Limitations of Outcome Studies 16
- Criticisms of Psychosocial Interventions for Carers 16
- Acceptance and Commitment Therapy 16
- ACT Model of Psychopathology 17
- ACT Model of Psychological Flexibility 20
- Empirical Support for ACT 23
- Evidence for the ACT Model 23
- Criticisms and Limitations of the Evidence Base of ACT 24
- Criticisms of the ACT Model 24
- Barriers and Challenges to Adopting ACT Principles 25
- Empirical Support for ACT with Family Carers of Children with IDs 25
- Limitations of ACT Research on Parents of Children with IDs 26
- Applicability of ACT for Family Carers of Adults with IDs 27

Chapter Two: Systematic Literature Review 28
- Chapter Overview 28
- Aims of Systematic Literature Review 28
- Methods 28
- Risk of Bias Assessment 32
- Results 32
- Intervention Effects 32
- Assessment of Risk of Bias: Randomised Studies 35
- Assessment of Risk of Bias: Non-Randomised Studies 36
- Critical Appraisal 37
- Discussion 38
- Systematic Literature Review Limitations 41
- Conclusion 42

Rationale for the Current Research 42
Chapter Three: Methods 43
Chapter Overview 43
Ontological Positioning 43
Epistemological Positioning 43
Research Paradigm 44
Design 44
Research Procedure 46
Measures 48
Method of Analysis 53
Group-Level Analyses 53
Test of Multivariate Normality & Equality of Multiple Variance-Covariance Matrices 54
Inferential Statistics 54
Non-Parametric Tests 54
Individual Analyses 55
Feasibility 59
Sample Size Calculation 59
Exclusion and Inclusion Criteria 59
Ethical Considerations 60
Dissemination 63
Chapter Four: Results 64
Chapter Overview 64
Demographics 64
Feasibility 68
Therapy Adaptations 71
Treatment Fidelity 71
Social Validity 72
Quantitative Feedback 72
Qualitative Feedback 73
Data Collection 76
Depression, Anxiety and Stress Scores at Baseline 76
Group-Level Analyses 77
Individual-Level Analyses 77
Participant Factors 81
Problematic and Values-Based Behaviours 82

Chapter Five: Discussion..87
Chapter Overview 87
Review of Study Findings..87
Demographics 87
Individual and Group-Level Analyses 88
Values-Based and Problematic Behaviours 97
Social Validity 100
Feasibility..101
Treatment Fidelity...101
Strengths 102
Limitations and Recommendations..104
Implications...108
Researcher Reflexivity..110
Conclusion 112
References...114
Appendices...146

Abstract

Introduction: It has been reported that family carers of adults diagnosed with intellectual disabilities experience significantly higher levels of psychological health difficulties than the United Kingdom general population. Acceptance and commitment therapy has been documented to be an effective intervention for a range of carer populations. A systematic literature review revealed that no studies have examined the efficacy of acceptance and commitment therapy for family carers of adults with intellectual disabilities.

Methods: Sixteen family carers of adults with intellectual disabilities were recruited and attended a six hour workshop based on acceptance and commitment therapy. Family carers completed six self-reported outcome measures relating to their mental health, quality of life, experience of caregiving, psychological flexibility and problematic and values-based behaviours. Outcome measures were collected at three time points: baseline, three weeks post-intervention and three months follow-up. Statistical analyses were conducted on outcome measures at group- and individual-levels.

Aims: This study investigated the feasibility, acceptability and effectiveness of an acceptance and commitment therapy workshop for family carers of adults with intellectual disabilities.

Results: Group-level analyses revealed that there were no significant differences between depression, stress, anxiety, quality of life, positive aspects of caregiving, mindful awareness, cognitive fusion and psychological flexibility scores across three time points. Individual-level analyses revealed that the majority of family carers' scores on outcome measures remained stable across time.

Discussion: The results revealed that overall there were limited improvements on outcome measures at group- and individual-levels. There were a number of potential explanations for these non-significant findings including the small sample size and insufficient statistical power. The strengths and limitations of this study were discussed, as well as the implications and research recommendations. Overall, the results indicated that acceptance and commitment therapy could be considered as an intervention for this carer population, however further research is required.

Chapter One: Introduction

Chapter Overview

This chapter provides an overview of the literature relevant to this study. The first section will briefly outline the social contexts of people with intellectual disabilities (IDs) in the United Kingdom (UK). The second section will summarise the positive and negative impacts of caregiving on family carers of individuals with IDs. This will include an exploration of sibling carers and a critical discussion of family carer research literature and policy. The third section will summarise the determinants of stress and psychosocial interventions within this carer population. This will lead to a critical appraisal of carer interventions. The fourth section will describe and review the theoretical basis of acceptance and commitment therapy (ACT), the ACT model of psychopathology and psychological flexibility, and empirical support for ACT. The fifth section will outline and appraise research evidence on ACT for family carers of children with IDs. The chapter ends with a rationale for the current study based on existing caregiver research.

Background

Intellectual disability (also referred to as learning disability) is characterised by significant impairments in three areas of functioning, namely impaired intellectual ability (an intelligence quotient below 70) and impaired social and adaptive abilities, plus evidence that these difficulties were present from childhood (World Health Organisation, 2019). The term intellectual disability (ID) will be used in this study as it is increasingly used in research, practise and policy in the UK (e.g., Cluley, 2018). An individual’s level of ID can be classified as mild, moderate, severe or profound based on their intellectual and adaptive abilities (World Health Organisation, 2019). It is estimated that in the UK there are approximately one and half million people with an ID (Parkin et al., 2018). Many people with IDs also have comorbid physical and/or mental health conditions, and therefore may be reliant on others to meet their health needs (Cooper et al., 2015). The majority of adults with IDs in England live within their family home (Hatton, 2017). Even if adults with IDs do not reside with their family, they typically receive emotional, practical and financial support from family members throughout their life (e.g. Mulvany et al., 2007; Seltzer et al., 2005).

Impacts of Family Caregiving

Research has revealed that caring for individuals with IDs can both positively and negatively impact numerous areas of families’ lives (e.g., Kearney and Griffin, 2001). Studies have typically focused on the negative consequences of caregiving (Bahador et al., 2023) and have frequently overlooked experiences of coping and resilience within these families (Grant and Whittell, 2000). Nonetheless, in recent years, research has increasingly explored these families’ strengths, protective factors, and the ways in which they thrive (e.g., Knight, 2013; Rajan and Romate, 2022).

Positive Aspects of Caregiving

Parents of adults diagnosed with IDs have reported numerous positive effects of caregiving across different relationships and aspects of their lives. On a personal level, this parent population have reported a sense of satisfaction and improvements in their purpose, confidence and personal strength (Beighton and Wills, 2019; Walden et al., 2000). Moreover, many parents have reported that they have developed new skills and perspectives on life, and enhanced their spiritual beliefs (Bahador et al., 2023). These parent carers have been reported to generally employ a diverse range of coping strategies, which can develop and expand as they age (Grant and Whittell, 2000; Llewellyn et al., 2010). At a relationship level, many parents have reported that their offspring with IDs have provided them with emotional support and a special connection (Beighton and Wills, 2019; Yoong and Koritsas, 2012). Additionally, this parent population have described their child as a source and/or expression of gratitude, love, pride, good luck, and joy (Beighton and Wills, 2019; Kearney and Griffin, 2001).

At a family level, parents of adults with ID have described strengthened relationships with family members and partners (Bahador et al., 2023; Fernández-Ávalos et al., 2020), as well as increased social interactions and networks (Yoong and Koritsas, 2012). At a societal level, some parents have used their lived experiences to become involved in activism, advocacy and academia work in relation to IDs (e.g. Good et al., 2017), and/or pursued a career in healthcare services (Murphy et al., 2007). Parents have also reported that they have developed increased empathy and compassion towards other people (Beighton and Wills, 2019). Overall, these findings are consistent with research demonstrating that caregiving can have numerous positive effects on multiple aspects of family members’ quality of life (e.g., Yoong and Koritsas, 2012). Moving forward, further research is required to explore if parents’ positive experiences of caregiving changes across their lifespan (Beighton and Wills, 2019).

Negative Aspects of Caregiving

Mental Health Impacts

The focus will now turn to considering the more difficult or negative aspects of caregiving. That said, to date, there has been a lack of research on the mental health impacts of caring for an adult with IDs in the UK (e.g., Grey et al., 2018). Grey et al. (2018) reported that family carers of adults with IDs experienced significantly higher psychological health difficulties than the UK general population. Nonetheless, much of the research on the impacts of caregiving have been based on parents of children with IDs and/or Autism Spectrum Conditions (ASCs). For example, parents of children with IDs have reported higher levels of parental stress and mental health difficulties than parents of children without IDs (Emerson, 2003; Hassall et al., 2005; Weiss, 2002). Compared with parents of non-disabled children, the likelihood of experiencing mental health difficulties increased two- to three-fold for mothers of children with IDs, and increased two and half to five-fold for parents of children with IDs and ASCs (Totsika et al., 2011).

In a study by Gallagher et al. (2008), it was found that for a third of parents of children with IDs depression scores fell within the clinical range, and half of parents' anxiety scores fell in the clinical range. However, none of the parents in the study by Gallagher et al. (2008) were receiving medication for anxiety or cognitive behavioural therapy (CBT). This finding was in line with previous research demonstrating a lack of formal support for this carer population (e.g. Power, 2009) and strengthens arguments to improve carer support provision (Arnold and McPherson, 2023). Within this parent population, the increased rates of stress, depression and anxiety symptoms have been reported to remain consistent over time (Gallagher et al., 2008; Glidden and Schoolcraft, 2003). Furthermore, symptoms of anxiety and depression experienced by parents of individuals with IDs were documented to significantly deteriorate during the COVID-19 lockdown (Willner et al., 2020). Taken together, these findings indicate the need for additional research to examine the particular factors which place family carers of individuals with IDs at an increased risk of experiencing mental health concerns (Arnold and McPherson, 2023).

Physical Health Impacts

Parents of children with IDs report more physical health difficulties and poorer physical health compared to parents of typically developing children. Possible mechanisms to explain these health disadvantages include increased chronic stress and stigma associated with caregiving (Gallagher and Whiteley, 2013; Song et al., 2018), Some parent-carers have voiced that their physical health had deteriorated after caring across their lifespan (Fernández-Ávalos et al., 2020), suggesting that older parents of individuals with IDs may be particularly at risk of negative physical health outcomes (Song et al., 2018). Research has also revealed that physical health problems are more likely to be experienced by mothers of individuals with IDs, possibly because they are more likely to be the primary carer (Allik et al., 2006; Gallagher and Whiteley, 2013). Equally, family carers of individuals displaying challenging behaviours are also more likely to experience poorer physical health outcomes (e.g., Gallagher and Whiteley, 2013). Nevertheless, as noted by Pinquart and Sörensen (2007), there are a number of methodological limitations of the research examining the relationships between caregiver stress and health. For example, most research has been based on caregivers' self-reports about health and therefore alternative measures should be used to collect and triangulate direct measures of physical health (Pinquart and Sörensen, 2007). In summary, future research should aim to improve the rigour of studies to more accurately explore the associations between poorer physical health and informal caregiving (Pinquart and Sörensen, 2007).

Interpersonal Relationships

Challenges associated with caregiving has been reported to cause a strain on familial relationships (Thompson et al., 2014). For example, family carers of individuals with IDs often have less opportunities to engage in leisure activities, and socialise with other family members (Thompson et al., 2014; Yoong and Koritsas, 2012). There is some evidence that caregiving for an individual with IDs can have a detrimental impact on parents' marital relationship (Caples and Sweeney 2011). Parents of adults with IDs have reported they had felt their child had been rejected and/or distanced from their family members and social network (Fernández-Ávalos et al., 2020). In a study by Fernández-Ávalos et al. (2020), the majority of parents reported a lack of support from family and friends, and consequently did not have sufficient time for self-care. Importantly, research has identified social support as a protective factor for families of individuals with IDs (e.g., Dew et al., 2019).

Caregiver Stigma

Family carers of people with IDs are exposed to higher levels of caregiver stigma than families of nondisabled individuals (Ali et al., 2012; Mitter et al., 2019; Song et al., 2018). This caregiver stigma may worsen throughout their relative's adult years as their ID becomes more visible (Shearn and Todd, 1997). Potential negative implications of stigma include family carers concealing and/or withdrawing from their caregiving role, as well as carers experiencing reduced self-esteem, social exclusion and isolation (Mak and Cheung, 2008; Mitter et al., 2019). These experiences of caregiver stigma also increase the risk of family carers experiencing depression and anxiety symptoms, and poor physical health (Mitter et al., 2019; Song et al., 2018). Song et al. (2018) recommended the development of policies, campaigns and interventions to reduce caregiver stigma and thereby alleviate the health disadvantages experienced by this carer population. Examples of anti-stigma interventions include educational approaches to increase knowledge of ID and approaches to increase contact with people with IDs (e.g., films and sporting events for individuals with disabilities) (see Seewooruttun and Scior, 2014). However, further research is warranted to develop and evaluate the effectiveness of anti-stigma interventions (Seewooruttun and Scior, 2014).

Finance and Employment Impacts

There is substantial evidence that families of individuals with IDs experience significant employment and financial impacts (Ouyang et al., 2014; Saunders et al., 2015). Parents of adults with IDs are less likely to have career opportunities (Yoong and Koritsas, 2012). They are more likely to give up employment, change career path, and stop or reduce their working hours per week to care for their child (Banda et al., 2022; Caples and Sweeney, 2011; Ouyang et al., 2014; Saunders et al., 2015). Overall, these studies indicate a significant loss of income for parents of individuals with IDs (Banda et al., 2022).

In the UK, families of individuals with IDs are significantly more likely to experience consistent poverty in comparison to families of individuals without IDs (e.g., Shahtahmasebi et al., 2011). For example, this parent population have reported paying additional financial costs on specialist services (e.g., day care services), healthcare, housing, and legal fees to set-up guardianship (Banda et al., 2022). Similarly, some parents of individuals with IDs have reported substantial financial costs to repair and/or replace property damaged by their offspring (Banda et al., 2022). Importantly, this financial insecurity and disadvantage is often experienced across their lifespan (Luckasson et al., 2017) and has been negatively associated with quality of life outcomes (e.g., Yoong and Koritsas, 2012). In recent years, this financial burden on family carers has been exacerbated within the context of the COVID-19 pandemic, and significant government cuts in funding public services and benefits (e.g., Warnock, 2023). Based on this research literature, Yoong and Koritsas (2012) recommended efforts to reduce the financial demands on parents of adults with IDs.

Long-term Challenges of Caregiving

Research has mainly focused on parents of children with IDs (Shearn and Todd, 1997). Nevertheless, family carers often experience additional challenges supporting their relative with IDs throughout adulthood. For example, people with IDs frequently find it more difficult or have been unable to access services during adulthood (Banda et al., 2022; Blomquist, 2006). These parents have also reported a paucity of day care and respite services for their adult children with IDs (Gauthier-Boudreault et al., 2019). This lack of service provision has resulted in increased care demands on families and negative effects on parental quality of life (Yoong and Koritsas, 2012). In addition, parents can often experience high levels of worry and anxiety related to the long-term housing and care arrangements for their adult relative with ID (Kruithof et al., 2021; Yoong and Koritsas, 2012). Moreover, there is evidence that parents of individuals with IDs may experience lower quality of life than parents of typically developing children (e.g., Leung and Li-Tsang, 2003). Furthermore, some parents of adults with IDs have reported that their quality of life had significantly deteriorated overtime (Fernández-Ávalos et al., 2020). Overall these additional, long-standing challenges indicate that families of individuals with IDs frequently require support across their lifespan (Banks, 2003; Yoong and Koritsas, 2012).

Sibling Family Carers

Services have frequently focused on supporting and working alongside parents, and the role and experiences of sibling carers has been under-researched (Davys et al., 2011). However, siblings can frequently take on important caring roles and responsibilities throughout the lifespan of adults with IDs (Avieli et al., 2019; Simpson, 2021; Stoneman, 2005). During childhood, non-disabled siblings often provide support to their learning-disabled sibling beyond the typical sibling relationship (Stoneman et al., 1989) and assume a caregiving role (Simpson, 2021). Many adults with ID are increasingly outliving their parents following improvements in life expectancies (Bigby, 2010). As a consequence, many siblings have reported concerns about the future care and residence of their sibling with ID (Davys et al., 2011).

Adult siblings can often be expected to increase their care involvement and/or assume a primary carer role when their parents are not able to provide care, for example in the event of parental ageing or death (Davys et al., 2011; Seltzer et al., 2005). This has resulted in some adult siblings experiencing feelings of resentment and/or frustration about providing care to their sibling with ID (Simpson, 2021). Other siblings have reported feelings of guilt when they are not able to contact and/or provide care to their sibling due to competing demands (Simpson, 2021). Nevertheless, siblings commonly provide support to their sibling with ID throughout their lifespan, even if they do not reside with them (e.g., Davys et al., 2011).

Based on this sibling research, a number of practice, policy and research recommendations have been proposed (see Simpson, 2021). Firstly, recommendations have been made to ensure siblings are included in interventions, decision-making, advocacy and future planning related to their disabled sibling (Davys et al., 2011; Simpson, 2021). Secondly, the research findings support a call for professionals to consider and support the needs of non-disabled siblings (Lee and Burke, 2018), and to support sibling relationships throughout the lifecycle (Simpson, 2021). Thirdly, findings indicate the need for policies and legislations to be inclusive of all family carers of individuals with IDs, including sibling carers (Lee and Burke, 2018; Simpson, 2021). Lastly, future research is required to explore the experiences of siblings, and develop and evaluate interventions to ameliorate the challenges related to sibling caregiving (Lee and Burke, 2018).

Criticisms of Family Research and Carer Involvement Policies

To date, research has revealed a number of positive and negative impacts of family caregiving, including the long-term challenges of caregiving for an adult with IDs. Nonetheless, it is important to note that there have been a number of criticisms of research on the experiences of families of individuals with IDs (see Knight, 2013). Firstly, some critics have argued that most of the research on families' experiences is based on mothers and therefore may not represent all family members' experiences (Knight, 2013; MacDonald et al., 2010). Secondly, research has been criticised for emphasising the importance of family carers' (mainly mothers) being able to psychologically adjust to their challenging circumstances and thus focuses on examining their personal strengths, weaknesses and internal characteristics related to resilience (Knight, 2013; McConnell and Savage, 2015). Knight (2013) has argued that this research focus may not fully take into account and/or minimise the socio-political influences on caregiving, and may even condone caregivers' experiences of marginalisation. This argument supports a call for carer interventions at a social-political level, including the development of public policy (McConnell and Savage, 2015).

Mental health and carer policies, such as the Care Act (UK Government, 2014), have been criticised for increasingly shifting the responsibility from the welfare state onto individuals, including family carers (e.g. Chard, 2022; Oulton and Heyman, 2009). For example, many family carers of individuals with IDs are responsible for the administration of personal budgets through direct payments instead of social services facilitating this (Chard, 2022). Importantly, this shift in responsibility onto family carers can have a number of possible negative impacts (e.g., Deacon et al., 2020). The individualisation of responsibility may exacerbate caregiving burden, result in worst clinical outcomes for both individuals and families (McPherson and Oute, 2021), and increase personal risk to family carers (Oulton and Heyman, 2009). Moreover, carer involvement can be detrimental to individuals where there are strained relationships and/or difficult family dynamics (McPherson and Oute, 2021). Overall, there has been a dearth of evidence to support this increase in carer involvement and shift in responsibility, highlighting an evidence-policy gap (e.g., McPherson and Oute, 2021).

Determinants of Parental Stress

There are a number of environmental, parent and child factors which interact and influence the stress levels of parents of individuals with IDs (Mash and Johnston, 1990). Equally, these factors may be affected by parental stress (Hassall et al., 2005), and therefore reflect a bidirectional relationship (e.g., Cappa et al., 2011). Child factors associated with higher parent stress include the increased severity of their child's ID, support needs (Grey et al., 2018), challenging behaviours (Lloyd & Hastings, 2009), and communication difficulties (Frey et al., 1989), as well as an ASC diagnosis (Staunton et al., 2023). Furthermore, parental factors associated with increased parental stress include having an external locus of control, emotion-focused coping styles (Hassall et al., 2005), negative appraisals about the family impact of their child's ID (Trute et al., 2007) and parents being younger (Llewellyn et al., 2010). Examples of environmental factors associated with increased parental stress include lower socio-economic status (Emerson, 2003), and lower levels of informal and formal support (Lloyd & Hastings, 2009; Park and Lee, 2022). Overall, these findings indicate that various factors impact parental stress (Hassall et al., 2005).

Interventions for Family Carers of Individuals with IDs

Psychosocial interventions have been found to reduce the negative impacts of caregiving and improve the quality of life and wellbeing of carers (see Neece and Lima, 2016). Furthermore, improvements in the mental health of family carers following these interventions can result in indirect positive effects on the wellbeing of individuals with IDs and their families (see Neece and Lima, 2016). A variety of psychosocial interventions have been delivered to parents of children with IDs including social care/respite interventions, systemic therapy, CBT, mindfulness and psychoeducation (Cowen and Reed, 2002; Hastings and Beck, 2004; Neece and Lima, 2016; Reid et al., 2016). Nevertheless, the provision of parent interventions and support are not equally accessible across this population (e.g., Yannamani et al., 2009). Behavioural parent training and parent-led support programs are commonly offered to this parent population (Neece and Lima, 2016), and therefore the outcomes and potential limitations of these interventions are detailed below.

Behavioural Parent Training

Behavioural parent training (BPT) has been shown to improve parents' ability to reduce their child's challenging behaviours, and improve parenting stress and behaviours (Lundahl et al., 2006; Neece and Lima, 2016; Ragni et al., 2022). Nevertheless, BPT interventions have been criticised for failing to address parental and environmental factors (e.g., parental stress and limited social support) which can negatively impact treatment effectiveness (O'Brien, 2011). For example, high levels of parental stress has been shown to negatively predict intervention outcomes for children with IDs (e.g., Brinker et al., 1994). Importantly, however, these interventions do not specifically attend to and/or address parents' stress, mental health, quality of life or wellbeing (Hastings and Beck, 2004; Neece and Lima, 2016).

Peer Support Programs

Parent-led support programs are the most common intervention offered to parents of children with IDs (Hastings and Beck, 2004; Neece and Lima, 2016) and can have a number of positive outcomes (Neece and Lima, 2016). These have included improvements in parental coping, quality of life, feelings of belonging, distress and isolation (Bray et al., 2017; Solomon et al., 2001). Qualitative evidence indicates that these parents have valued developing relationships and learning from others in similar circumstances, and feeling mutually supported and understood (Bray et al., 2017; Dew et al., 2019). Nonetheless, Sartore et al. (2021) completed a recent review on family carers of children with complex needs (including IDs), and concluded that there was no quantitative evidence to support the effectiveness of peer support interventions. Overall, there has been a dearth of research evaluating the effectiveness of peer support interventions (Neece and Lima, 2016; Solomon et al., 2001). For these reasons, peer support programs are recommended to complement professional support, particularly as these parents may benefit from both types of support (Dew et al., 2019).

Methodological Limitations of Outcome Studies

There are a number of methodological limitations of studies examining interventions for family carers of individuals with IDs (Hastings and Beck, 2004). For example, the majority of research on the effects of psychological interventions on parents of individuals with IDs has been based on white, educated, middle-class mothers (Leung and Li-Tsang, 2003; Singer et al., 2007). However, the experiences and needs of family carers may vary across demographics such as gender (Roberts et al., 2006), and therefore may require different interventions (MacDonald et al., 2010). Hence, additional research is required to make conclusions about the most effective intervention for family carers of adults with IDs (Hastings and Beck, 2004).

Criticisms of Psychosocial Interventions for Carers

The majority of psychosocial interventions for parents (e.g. behavioural parent training) have been criticised as they do not address parenting stress, but focus on improving parenting skills to manage problematic behaviours exhibited by their children (Neece and Lima, 2016). Similarly, as noted by Deacon et al. (2020), interventions for family members aim to improve their wellbeing in order to continue their carer role, rather than for their own benefit. For these reasons, the provision of these interventions makes parents of individuals with IDs responsible to oversee and provide specialist care to their children, and manage risks (e.g. Oulton and Heyman, 2009). For these reasons, it has been argued that psychosocial interventions for family carers of individuals with IDs are ideologically and economically motivated to reduce welfare state provision, rather than being focused on carers’ wellbeing (Chard, 2022; Deacon et al., 2020). Towards this end, Powers et al. (2009) have argued that policies need to redistribute the responsibilities of care and acknowledge the relational and collective nature of care.

Acceptance and Commitment Therapy

Having reviewed the literature on caregiver stress and associated interventions, this chapter will now change focus to introduce and describe the ACT model and how it has so far been used to support family carers of children with ASC and ID.

Theoretical Basis of ACT

In recent years, a third-wave CBT model known as ACT has been increasingly used as a psychological intervention for a range of populations (e.g., Harris, 2019). ACT is based on relational frame theory (RFT), radical behaviourism and functional contextualism (Hayes et al., 2003; Twohig, 2012). Whilst it is beyond the scope of this thesis to fully describe RFT and functional contextualism, some of the applications and principles of these theories are briefly described in this chapter.

Relational Frame Theory

Relational frame theory (RFT) is a theory of human cognition and language (Harris, 2009). The main principles of RFT have been supported by an accumulation of research evidence (see Dymond et al., 2010). RFT asserts that human behaviour is predominantly governed by relational frames. This refers to the human ability to automatically develop internal relations between numerous external events, and cognitions and feelings without direct teaching or experience (Hayes, 2004). Relational frames are posited to potentially increase psychological distress as learned relational frames guide behaviour and can be difficult to break down (Hayes, 2004; Smith, 2017). Based on RFT, the goal of ACT is to support individuals to expand their relational frame network to form more helpful relational frames (Blackledge, 2003), namely to develop more helpful links between events and cognitions and feelings (Blackledge, 2003). On this basis, RFT aims to reframe and change an individual's relationships with their internal experiences (i.e. thoughts, feelings, sensations) instead of the frequency, form or intensity of these experiences (Hayes et al., 1999; Harris, 2009). For more information on RFT see Barnes-Holmes et al. (2004) and Blackledge (2003).

Principles of ACT

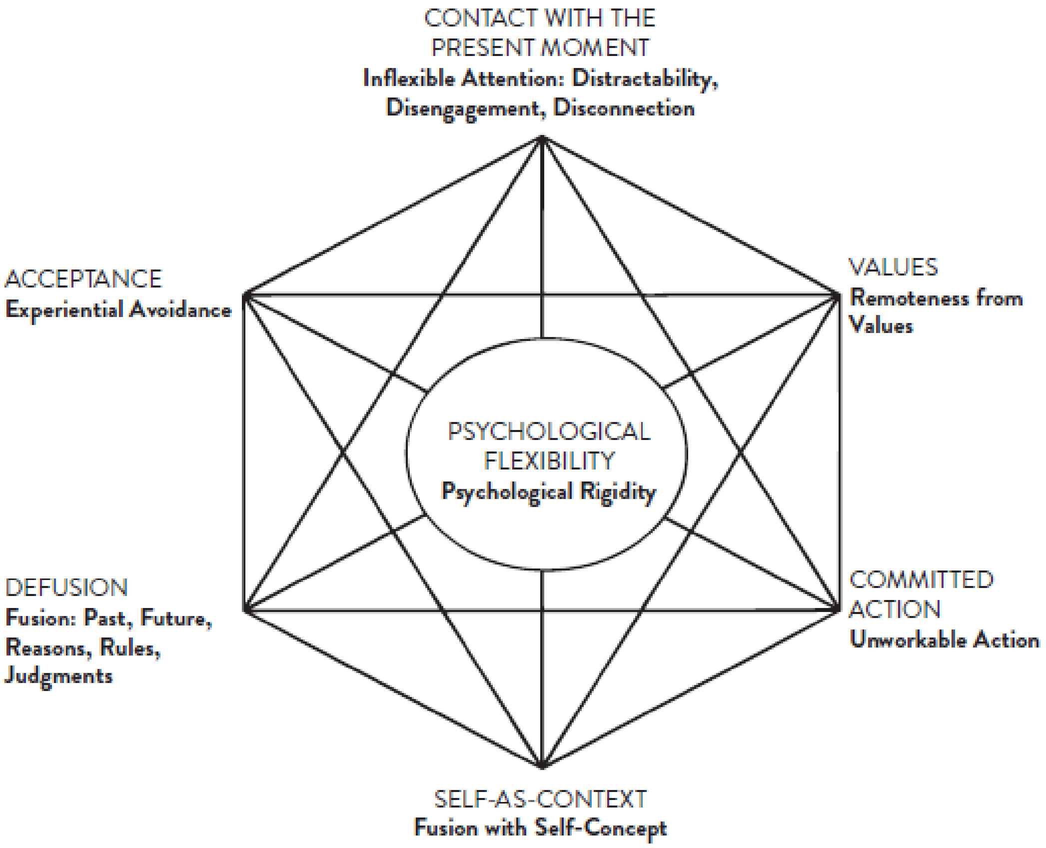
ACT does not aim to target specific disorders and/or reduce symptoms, and is not a diagnostic specific therapy (Luoma et al., 2007; Smith, 2017). It is a transdiagnostic approach which can be used to address key processes across a range of diagnoses and difficulties (Harris, 2019). In ACT, a number of experiential exercises, metaphors and paradoxes are employed to help individuals understand the six ACT processes (Harris, 2019). ACT interventions are not implemented in a structured or ordered sequence, but rather the techniques are used and adapted to meet each person's needs (Harris, 2019).

ACT Model of Psychopathology

The ACT model of psychopathology asserts that suffering and pain naturally emerges from covert (e.g. thoughts) and overt language (i.e. behaviour) processes formed by the human mind (Hayes et al., 1999; Luoma et al., 2007). More specifically, there are six core pathological processes claimed to lead to psychological inflexibility, and the development and maintenance of mental health difficulties (Harris, 2019). These processes are cognitive fusion, experiential avoidance, loss of present moment awareness, remoteness from personal values, unworkable action, and fusion with self-concept (Figure 1). These core processes are briefly outlined below.

Figure 1

ACT Model of Psychological Inflexibility



Note. Image retrieved from Harris (2019), ACT made simple: An easy-to-read primer on acceptance and commitment therapy (page 33).

Cognitive Fusion

Cognitive fusion refers to the process of taking the content of cognitions literally or as absolute truths, so they dominate and/or negatively impact attention and behaviour (Harris, 2019).

Experiential Avoidance

Experiential avoidance means attempting to avoid, fight or reduce the frequency and severity of inner experiences (Luoma et al., 2007). Avoidance can paradoxically increase the frequency and severity of internal experiences and thereby increase psychological suffering (Harris, 2019). It can also lead to behaviour that is not meaningful or life-enhancing (Hayes et al., 1999).

Loss of Present Moment Awareness

Loss of present moment awareness means to not fully contact the present moment (both internal and external events). As a consequence, behaviour is typically dictated by cognitive fusion and experiential avoidance, and disconnected from values (Luoma et al., 2007).

Remoteness from Values

Remoteness from values is defined as a lack of clarity and/or contact with personally held values (Luoma et al., 2007).

Unworkable action

Unworkable action involves engaging in behaviour which is ineffective and/or inconsistent with personal values and mindful awareness (Harris, 2019).

Fusion with Self-Concept

Fusion with self-concept involves taking positive and negative thoughts and/or evaluations about oneself literally or as absolute truths (Harris, 2019).

Psychological Inflexibility in Caregivers

Based on the ACT model, family carers with higher levels of psychological inflexibility may: (a) take their thoughts literally (e.g., ‘I should be able to cope and support my relative on my own’), (b) try to avoid emotions, situations or thoughts (e.g. feelings of frustration, sadness and anxiety related to caregiving), (c) become preoccupied with past or future events (e.g., ruminate about their relative’s future care and accommodation arrangements), (d) not know or connect to what is important to them, (e) engage in behaviour which is inconsistent with their values (e.g., avoid social interaction when they value connection with others), and (f) take thoughts about themselves as a carer and/or person literally (e.g., ‘I’m a bad parent’).

Functional Contextualism

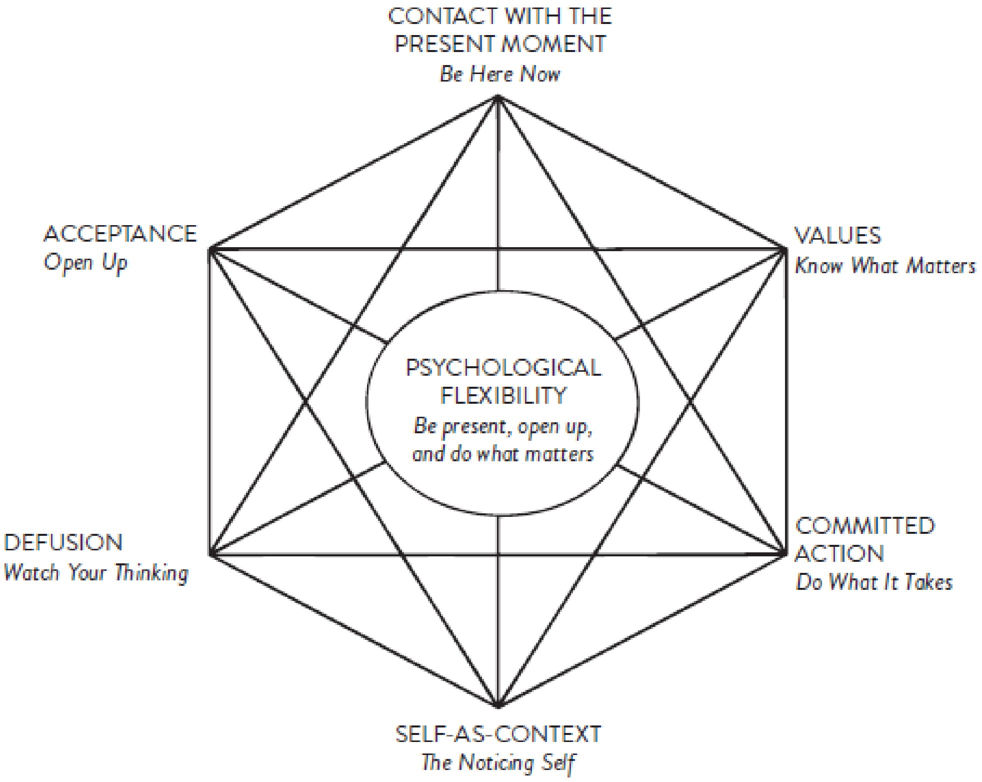
Functional contextualism posits that internal events (e.g. cognitions, feelings or memories) are not viewed as unhelpful or problematic, but rather the context alters the function of inner experiences (Harris, 2009). For example, within a context of experiential avoidance and cognitive fusion, internal events are more likely to function in a way which is unhelpful or inconsistent with personally held values (Harris, 2009). On the other hand, within a context of cognitive defusion and acceptance, these internal events are more likely to function in a way which is helpful and values-congruent (Harris, 2009). In ACT, individuals are taught to observe and become aware of how their own covert and overt behaviours function in their lives (Harris, 2019). In line with functional contextualism, ACT focuses on evaluating the workability of cognitions (i.e. whether the cognitions help to move towards values-based living), in comparison to CBT which focuses on the validity of thoughts (Luoma et al., 2007; Ruiz, 2010).

ACT Model of Psychological Flexibility

The aim of ACT is to address psychological rigidity by developing psychological flexibility (Luoma et al., 2007). Psychological flexibility is defined as the ability to be present in the moment, respond to internal events without resisting or avoiding, and engage in behaviours consistent with personal values (Harris, 2019). There are six core ACT processes which are hypothesised to increase psychological flexibility: present moment awareness, acceptance, defusion, self-as-context, values and values-based action (Hayes et al., 1999). These core processes are interconnected (Harris, 2019) and have been outlined below (See Figure 2).

Figure 2

ACT Model of Psychological Flexibility



Note. Image retrieved from Harris (2019), ACT made simple: An easy-to-read primer on acceptance and commitment therapy (page 6).

Contact with the Present Moment

Contact with the present moment involves paying attention and fully engaging with internal and/or external experiences in the here-and-now (Harris, 2019; Luoma et al., 2007). This involves focusing awareness on experience from a non-judgemental, open and curious stance (Harris, 2019).

Cognitive Defusion

Cognitive defusion (also called deliteralization) means not perceiving the content of cognitions (e.g., thoughts, images, memories) literally or as absolute truths (Harris, 2019). It involves distancing oneself from the cognitions, so they have less influence over attention and behaviour (Luoma et al., 2007).

Acceptance

Acceptance refers to the process of opening up and making full contact with internal experiences (e.g., body sensations, urges and emotions) (Harris, 2019). It involves allowing both unwanted and wanted internal experiences to be present, without attempting to resist, avoid, or reduce the frequency and/or severity of these events (Harris, 2019; Luoma et al., 2007).

Self-as-context

Self-as-context refers to part of the self which notices and observes all internal and external experiences (Harris, 2019). The aim in ACT involves developing a continuous and consistent sense of self which is separate from the events experienced (Harris, 2019), which also fosters acceptance (Luoma et al., 2007). ACT also aims to notice and not take self-evaluations literally (Luoma et al., 2007).

Values

Values refer to personally important life directions and chosen ways of behaving and living (Harris, 2019). In ACT, values are important in guiding and pursuing a meaningful and valued life (Harris, 2019). Values cannot be fully completed or achieved (compared with goals), but consist of ongoing, moment to moment values-based action (Luoma et al., 2007), Values can be used to identify behavioural goals in ACT (Harris, 2019).

Committed Action

Committed action (also known as values-based action) means taking effective physical and/or psychological action guided by personally important values (Luoma et al., 2007). Through taking committed action, individuals tend to experience unwanted inner states (Harris, 2019), which may act as internal barriers to committed action (Luoma et al., 2007). For this reason, individuals will often need to actively implement and/or develop their ACT skills (e.g. defusion and acceptance) to persist with valued action (Harris, 2019).

Psychological Flexibility in Caregivers

In line with the ACT model, family carers with higher levels of psychological flexibility may: (a) notice, acknowledge, and/or normalise their thoughts, images and memories (e.g., 'I'm noticing an upsetting image of my relative'), (b) make space for their emotions, urges, body sensations, and thoughts associated with caregiving (e.g. notice and allow themselves to feel tired, frustrated and sad), (c) flexibly pay attention to the present moment whilst caregiving (e.g., savour and enjoy experiences with their relative), (d) be aware of what is important to them, (e) engage in behaviour which is consistent with their values (e.g., attend personal health appointments when they value self-care), and (f) allow thoughts about themselves as a carer and/or person to come and go, and not take them literally (e.g., ‘I’m a good parent’).

Empirical Support for ACT

An accumulation of research indicates that ACT can be effective for individuals experiencing a range of mental and physical health problems (see A-tjak et al., 2015; Gloster et al., 2020; Ruiz, 2010). Gloster et al. (2020) completed a review of 20 meta-analyses of ACT studies, which included a total of 133 studies. The authors reported that ACT was effective across a range of mental health diagnoses (e.g. depression, anxiety, eating disorders and substance misuse) and physical health conditions (e.g. chronic pain), with largely similar effects reported across diagnoses. Moreover, Gloster et al. (2020) also reported that ACT was associated with small to medium effects sizes for quality of life, small to large effect sizes on psychological flexibility, and small to medium effect sizes on wellbeing and functioning. Based on these findings, Gloster et al. (2020) posited that ACT can be considered as effective as CBT.

As a transdiagnostic approach, there is preliminary evidence to suggest that ACT may be particularly effective for individuals experiencing comorbid mental and physical health conditions (e.g., Dindo et al., 2017; Juarascio et al., 2010). More recently, based on recent evidence, NICE guidelines have recommended that ACT should be considered as a psychological intervention for chronic primary pain (National Institute for Health and Care Excellence, 2021). In addition, ACT has been shown to improve mental health and wellbeing outcomes for a range of informal caregivers, including family carers of individuals with dementia, autism, psychosis, acquired brain injury and children with IDs (Fowler et al., 2021; Han et al., 2021; Kishita et al., 2022; Magnacca et al., 2021; Reid et al., 2016). Overall, there is substantial evidence that ACT is an effective intervention for people with a range of mental health difficulties and needs (Gloster et al., 2020).

Evidence for the ACT Model

There has been an accumulation of empirical evidence to support the principles of relational frame theory underpinning ACT (Hayes et al., 2006; O’Connor et al., 2017). Similarly, mediational studies have been used to test the psychological flexibility model, as well as the mechanisms of change in ACT (Levin et al., 2012; Stockton et al., 2019). A systematic review of ACT mediation studies revealed that changes in psychological flexibility mediated improvements in mental health outcomes, functioning and physical health symptoms (See Stockton et al., 2019). These findings were consistent with a previous meta-analyses of ACT mediational studies (See Hayes et al., 2011). Moreover, a review of component studies indicated that experiential avoidance has been significantly associated with a range of mental health difficulties, including anxiety and depression symptoms (see Ruiz, 2010). Overall, these findings provide further support for the psychological flexibility model underlying ACT (Hayes et al., 2011; Levin et al., 2012).

Criticisms and Limitations of the Evidence Base of ACT

There have been a number of emerging critiques about the evidence base of ACT (See Gaudiano, 2011). Based on a meta-analysis, Öst (2008) reported that all 13 randomised controlled trials on ACT had methodological limitations (e.g., co-intervention bias and a lack of treatment fidelity checks and measures). The author concluded that the ACT studies were less rigorous than CBT studies and did not meet the criteria for empirically validated therapies (see Chambless et al., 1998). In a review by Ruiz (2010), it was reported that there was initial evidence from six studies that ACT demonstrated better outcomes than CBT. However, based on extant literature, researchers have concluded that it remains unclear if ACT is significantly better than existing evidence-based therapies, including CBT (Gaudiano, 2011; Gloster et al., 2020). Therefore, further research is required to investigate this (Hayes et al., 2006).

Criticisms of the ACT Model

The theoretical basis of ACT has received criticism (see Gaudiano, 2011). Specifically, it has been argued that the conceptualisation and definition of psychological flexibility remains unclear and lacks consensus (Malo et al., 2022). Moreover, research on the relationship between psychological inflexibility and psychopathology is correlational, and therefore causality has not been established (Malo et al., 2022). Hofmann and Asmundson (2008) have claimed that ACT does not constitute a third wave cognitive therapy and that both ACT and CBT can be conceptualised using a similar model and/or change processes (Hofmann and Asmundson, 2008). In a similar vein, Stockton et al. (2019) completed a systematic review of mediation studies and concluded that there was a lack of evidence to support the equal weight given to the six core processes underpinning psychological flexibility. More specifically, the authors reported that only one study had completed a mediation analysis for values and present moment awareness, and no mediation studies had examined self-as-context. On this basis, researchers have proposed that future research is required to investigate the links between the specific ACT processes and the theoretical basis of ACT (e.g., Hayes, et al., 2006; O'Brien, 2011).

Barriers and Challenges to Adopting ACT Principles

Based on qualitative evidence, some individuals have found it difficult to understand and/or implement ACT concepts (e.g., acceptance), particularly when they are feeling distressed and/or overwhelmed (e.g., Bacon et al., 2014). Other researchers have reported that some participants have misapplied ACT techniques (e.g., defusion and mindfulness) as experiential avoidance techniques (Bloy, 2013; Smith, 2017; Wardley et al., 2016). For instance, some clients have reported using defusion as a way of disputing their thoughts (e.g., Bloy, 2013; Smith, 2017). Studies have also reported that clients can often struggle to foster an acceptance agenda and thus may experience feelings of disappointment when the ACT intervention did not change and/or cure their difficulties (Harrison, 2012). One possible explanation for this was that clients have often received long-standing messages from others and more generally from western society, in accordance with the agenda to control private experiences (e.g., Luoma et al., 2007; Smith, 2017). For these reasons, it has been suggested that some individuals may require more time and/or further sessions to develop their understanding of ACT (Bacon et al., 2014).

Empirical Support for ACT with Family Carers of Children with IDs

To date, research has focused on ACT for parents of children with ASC (Chua and Shorey, 2021). Only three quantitative studies have examined the effectiveness of ACT interventions for family carers of children with IDs (Lobato et al., 2022; Poddar et al., 2015; Saeedifard et al., 2016). Of these, two studies only included mothers in their study (Poddar et al., 2015; Saeedifard et al., 2016). Lobato et al. (2022) did not state the specific family members included, although 83 per cent of their sample were female. From pre-intervention to follow-up, these studies reported significant improvements in anxiety, depression, psychological flexibility (Lobato et al., 2022; Poddar et al., 2015), resiliency (Saeedifard et al., 2016), stress, psychological distress, thought suppression, and positive and negative family interactions (Lobato et al., 2022). Moreover, Lobato et al. (2022) reported that the intervention gains had accelerated at two months post-intervention. However, due to the paucity of research, further quantitative research is required to replicate these preliminary findings.

Only one qualitative study by Reid et al. (2016) has examined the effectiveness and experiences of ACT for parents of children with IDs. However, the sample included only mothers of children with severe IDs, autism and challenging behaviours. In this study, all mothers reported positive intervention effects on them and their children. More specifically, these mothers reported that they felt socialising with peers enabled them to feel more hopeful, less stressed, and more compassionate and validating towards themselves. Additionally, these mothers also spoke about feeling more able to cope with stressors and respond in different ways. Some mothers described feeling able to talk about parts of their parenting experience (e.g. experiencing challenging behaviours directed towards them) which they would not have done otherwise. Some mothers described barriers and challenges to implementing formal and informal mindfulness practise, however most mothers felt that they incorporated mindfulness into their daily lives. Future research is required to replicate these initial qualitative findings, and to examine the experience and effects of ACT across different family carer populations and services (Reid et al., 2016).

Limitations of ACT Research on Parents of Children with IDs

There are several limitations of the research studies on ACT for parents of children with IDs. The three ACT studies on parents of children with IDs did not collect measures of treatment fidelity (Lobato et al., 2022; Poddar et al., 2015; Saeedifard et al., 2016). Therefore, it was not possible to confidently attribute the findings to the ACT processes implemented (Plumb and Vilardaga, 2010). Similarly, these studies did not collect measures of social validity, and therefore it was not possible to determine the social acceptability of the ACT groups (Garcia et al., 2021). Lastly, these studies did not include a range of family carers (e.g. siblings) of adults with IDs and two studies only collected outcome measures immediately at post-intervention (Poddar et al., 2015; Saeedifard et al., 2016). As a consequence, the long-term maintenance of treatment gains could not be determined.

To the writer’s knowledge, no studies have investigated the effectiveness of ACT for family carers of adults with IDs. This lack of research on ACT for family carers of adults could be explained by the different approaches of child and adult learning disability (LD) services. Namely, research has revealed that adult LD services tend to focus on individuals and therefore are less likely to offer carer interventions, in comparison with child LD services which are more family-focused (e.g., Brown et al., 2019). Hence, future research is required to investigate the effectiveness of ACT for family carers of adults with IDs.

Applicability of ACT for Family Carers of Adults with IDs

Based on empirical evidence in support of ACT across a number of informal carer groups (e.g., Han et al., 2021; Magnacca et al., 2021), it therefore stands to reason that ACT may also be effective for family carers of adults with IDs. Moreover, the unique needs and challenges of this carer population may align with the goals of ACT (e.g., Blackledge, 2004). It has been suggested that the acceptance of unwanted internal experiences could be particularly helpful for this carer population (MacDonald et al., 2010). Firstly, many unwanted thoughts experienced by family carers of adults with IDs might be true (e.g. cognitions related to caregiver demands or stigma) and therefore are unlikely to benefit from cognitive restructuring (Blackledge, 2004). Secondly, family carers may not be able to change their unpleasant inner experiences and personal situation, and thus might benefit from fostering acceptance towards their unchangeable circumstances (Fowler et al., 2021; Juvin et al., 2021). Thirdly, some parents of individuals with IDs have reported difficulties fully accepting their child's ID diagnosis and have expressed ongoing feelings of grief and sadness (Fernández-Ávalos et al., 2020). Research has revealed that parental acceptance of internal experiences (e.g. related to their child with ID) has been negatively correlated with parental mental health difficulties and positively correlated with parental wellbeing (e.g., MacDonald et al., 2010). Similarly, high levels of caregiver psychological inflexibility has been positively correlated with higher levels of mental health difficulties and caregiver burden (e.g., Tan et al., 2023). Overall, these findings suggest that ACT may be an effective intervention for family carers of adults with IDs (Lobato et al., 2022; MacDonald et al., 2010). This study will be the first to systematically explore the effects of ACT within this carer population.

Chapter Two: Systematic Literature Review

Chapter Overview

This chapter provides a detailed examination of the literature on ACT interventions for family carers of individuals with IDs and/or ASCs, which helped to inform the exact focus of this study. This chapter starts by detailing the aims of the systematic review, search strategy, inclusion and exclusion criteria, and data extraction procedure. This is followed by a narrative review and critical appraisal of the quality of the studies included. The chapter ends with a rationale for the current research study based on the findings of the literature review.

Aims of Systematic Literature Review

The purpose of this literature review was to examine the effects of ACT interventions for family carers of individuals with IDs and/or ASCs across a number of outcome measures, including wellbeing, mental health (e.g. stress), quality of life and skills that improve psychological flexibility (e.g. cognitive defusion and awareness states). The second objective was to critically appraise the quality of the studies included in this literature review and to provide a rationale for the current study.

Methods

Search Strategy

On 20th April 2023, a search was conducted using eight databases including: PsycINFO, CINAHL Ultimate, EMCARE, AMED, HMIC, PsycARTICLES, EMBASE and Medline. The search strategy involved using the “abstract” option for all searches. The search terms below were used:
(intellectual AND disab*) OR (learning AND disab*) OR “IDD*” OR “ID*” OR “LD*” OR (mental* AND retard*) OR (mental* AND handicap*) OR (developmental* AND disab*) OR “Autis*” OR “ASC” OR “ASD” OR “Autism Spectrum Condition*” OR “Autism Spectrum Disorder” OR “Asperger*” AND “Acceptance and Commitment Therapy” OR “Acceptance and Commitment Training” OR "Acceptance and commitment" AND "Parent*" OR "Carer*" OR "Caregiver*" OR "Guardian*" OR "Mother*" OR "Father*" OR "Sister*" OR "Brother*" OR "Sibling*" OR “Grandparent*” OR “Relative*” OR "Famil*".

To increase the number of papers found, forward citation searching was used, and the citation lists of the included studies and seven relevant systematic literature reviews were reviewed (Byrne et al., 2021; Garcia et al., 2021; Gur and Reich, 2023; Han et al., 2021; Juvin et al., 2021; Magnacca et al., 2021; Merriman et al., 2020).

Inclusion Criteria

Studies had to meet the inclusion criteria below to be included:

Population: Family carers of individuals diagnosed with ID and/or ASC were eligible. Both populations were included due to a paucity of ACT research exclusively on family carers of individuals diagnosed with ID. There were no restrictions on the age of individuals diagnosed with IDs and/or ASC, or the methods used to confirm their diagnoses to increase the number of articles. Family carers included members of biological, foster and/or step families (e.g. parents, stepsiblings, grandparents) of any age who were supporting their relative.

Intervention: Studies were included if the intervention was based on a minimum of one core ACT process. There were no restrictions on the frequency, length or format of the intervention (e.g. virtual, self-guided, telephone or group), or the qualification, experience or role of the facilitator.

Comparator or control group: Articles with or without any control groups were eligible. There were no restrictions on the type of control group. For example, treatment as usual (e.g. counselling), no treatment, attention placebo and wait-list control groups were all eligible.

Outcomes: Articles with pre- and post-intervention quantitative data were included to evaluate the intervention effectiveness. All types of outcome measures were eligible including participant, family and clinician informed questionnaires (e.g. wellbeing, mental health symptoms, quality of life, shame, familial interactions and stress), direct measures of behaviour and ACT process outcome measures (e.g. questionnaires in relation to awareness states and thought suppression).

Study design: All study designs were eligible including randomised control trials and non-randomised studies (e.g. single group pretest-posttest design, case series design, multiple baseline design, single case design and non-randomised control trials). There were no restrictions on the publication date and quality appraisal rating of studies. Taken together, this criteria was employed to minimise the risk of study selection bias (Ahmed et al., 2012). All studies had to be written in the English language due to the absence of translation services.

Exclusion Criteria

To be excluded from this systematic review, the study had to meet one of the following exclusion criteria:

Population: Studies that included family carers of individuals with other presentations (e.g. ADHD and other neurodevelopmental disorders) were excluded to only examine the effects of ACT for family carers of individuals with IDs and/or ASCs as these diagnoses commonly co-exist (e.g., Dunn et al., 2020; Postorino et al., 2016).

Intervention: Articles were excluded if the intervention was non-ACT based (e.g. parent training interventions) and only mindfulness-based (e.g. mindfulness-based stress reduction) as these interventions are not based on the core ACT processes. Studies were excluded if the ACT intervention was delivered in conjunction with other interventions (e.g. counselling) to minimise the possibility of co-intervention bias (Armijo-Olivo et al., 2022).

Outcomes: Studies without pre- and post-intervention data and statistical analyses were excluded as this was needed to assess the clinical and/or statistical significance of ACT.

Study Design: Qualitative or mixed methods designs, book chapters, book reviews and systematic reviews (e.g. meta-analyses and narrative reviews) were excluded as this review aimed to evaluate primary, quantitative research. Non-peer reviewed articles (e.g. theses and dissertations) were excluded to improve the rigour and quality of the evidence examined (Kelly et al., 2014).

Data Extraction and Synthesis

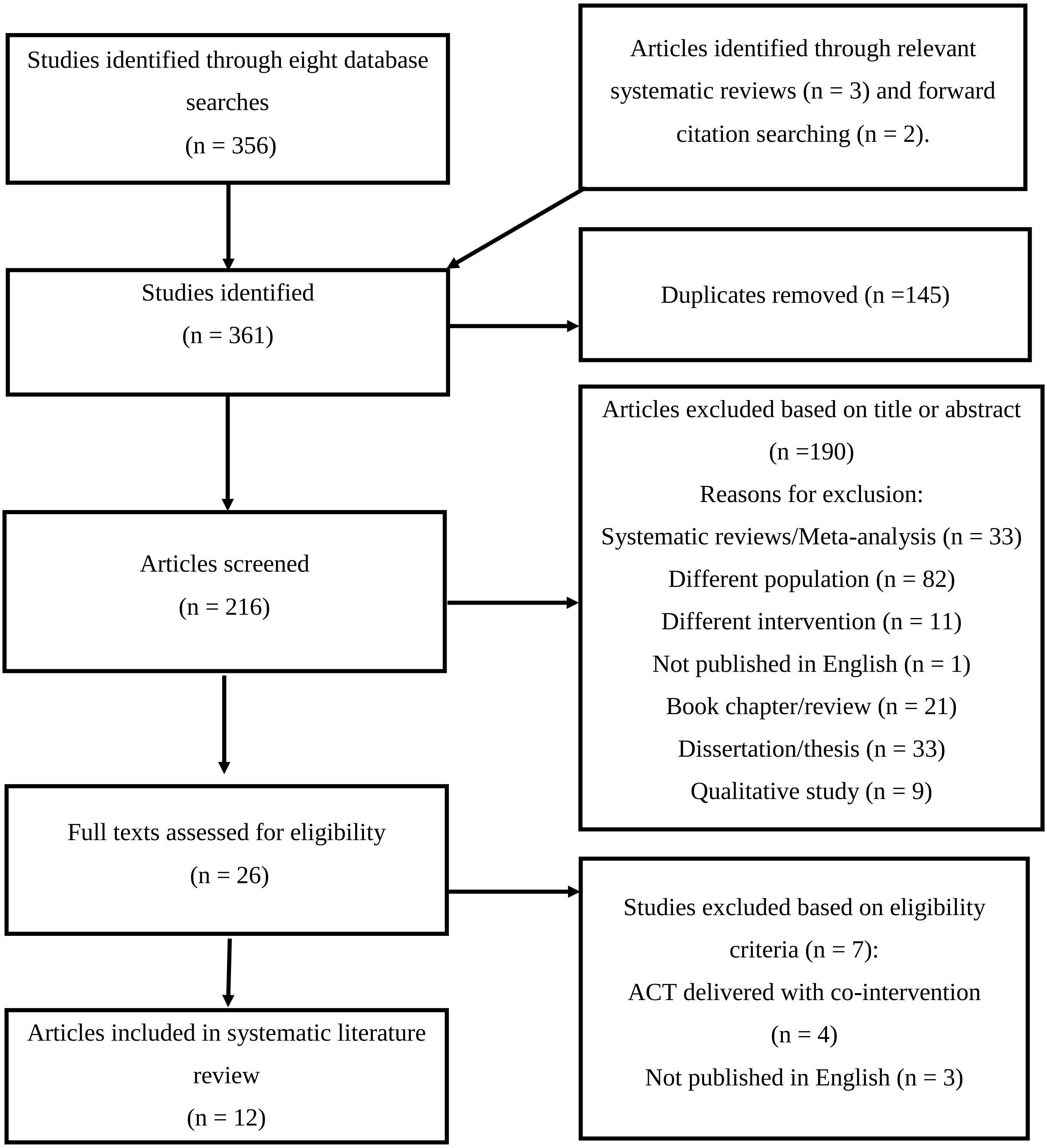
The studies were initially screened according to their titles and abstracts against the inclusion and exclusion criteria (see Figure 3). The eligibility criteria was then used to screen the full-text articles identified. Subsequently, the key characteristics of each study were extracted, checked and documented in Appendix A by one reviewer due to the time frame of a doctoral thesis, and restrictions of being a trainee clinical psychologist on the doctorate.

Statistical Analysis

As there was significant clinical and methodological heterogeneity across studies, a meta-analysis was not completed in this review (Gagnier et al., 2012). Specifically, the causes of clinical heterogeneity related to diversity in the baseline data of participants (e.g. demographics and outcome measures), and the intervention frequency, length and techniques. In addition, there were differences in the timing and type of data collected. Causes of methodological heterogeneity related to the discrepancies in the comparators and designs employed by studies. Notably, meta-analyses were not completed in three similar reviews based on significant heterogeneity (Byrne et al., 2021; Jin et al., 2021; Juvin et al., 2021). As such, the results were summarised based on a narrative synthesis (Campbell et al., 2018, 2020).

Figure 3

Flowchart of study selection



Risk of Bias Assessment

Two assessment tools were used to evaluate the risk of bias. The Risk Of Bias In Non-randomized Studies of Interventions assessment tool (ROBIN-I; Sterne et al., 2016) was used to assess non-randomised studies. The Revised Cochrane risk-of-bias tool for randomized trials was used to assess randomised control trials (RoB 2; Sterne et al., 2019). The domain and overall risk of bias scores were rated for each study by one reviewer as another reviewer was not available. The reviewer accessed training videos provided by Cochrane to increase the accuracy of risk of bias scores. These quality appraisal tools were selected based on previous systematic reviews of ACT interventions (e.g. Garcia et al., 2021).

Results

Intervention Effects

Statistical Significance

As shown in Table 1 and Appendix A, all twelve studies used outcome measures based on participants' self-report. In six studies with control groups, at post-test there were significant improvements in the ACT groups in psychological flexibility (Marino et al., 2021), mindfulness (Corti et al., 2018), experiential avoidance (Hahs, et al., 2019; Joekar et al., 2016), awareness states (Hahs, et al., 2019; Marino et al., 2021), depression (Hahs, et al., 2019; Joekar et al., 2016), cognitive fusion (Hahs, et al., 2019), internalised shame (Hahs, et al., 2019), values (Hahs, et al., 2019; Marino et al., 2021), resiliency (Saeedifard et al., 2016) and emotion regulation (Salimi et al., 2019), compared to the control group. Nevertheless, at post-test there were no significant differences between ACT and control groups on anxiety, quality of life (Joekar et al., 2016), stress (Corti et al., 2018; Joekar et al., 2016; Marino et al., 2021), cognitive fusion (Corti et al., 2018), mindfulness (Hahs, et al., 2019), thought suppression (Hahs et al., 2019) and parents' perception of their child's behaviours (Marino et al., 2021). None of the six studies with control groups collected follow-up data.

In the six studies without control groups, from pre- to post-intervention studies reported significant improvements in depression symptoms (Blackledge and Hayes, 2006; Jogdand and Magar, 2020; Lunsky et al., 2017; Poddar et al., 2015), anxiety symptoms (Jogdand and Magar, 2020; Poddar et al., 2015), stress (Jogdand and Magar, 2020; Lobato et al., 2022; Lunsky et al., 2017), physical health (Lunsky et al., 2017), psychological distress (Blackledge and Hayes, 2006; Lobato et al., 2022), valued-living (Fung et al., 2018), psychological flexibility (Fung et al., 2018; Lobato et al., 2022; Poddar et al., 2015), cognitive fusion (Fung et al., 2018; Blackledge and Hayes, 2006), thought suppression (Lobato et al., 2022), familial interactions (Lobato et al., 2022), and psychological quality of life (Poddar et al., 2015). Alternatively, there were no significant differences pre- and post-intervention in experiential avoidance, general psychiatric problems (Blackledge and Hayes, 2006), and three quality of life domains (Poddar et al., 2015). Five studies gathered data at follow-up. Of these, the significant improvements in ACT processes and mental health outcomes were maintained at follow-up (Blackledge and Hayes, 2006; Fung et al., 2018; Joekar et al., 2016; Lunsky et al., 2017), and accelerated over time in one study (Lobato et al., 2022).

Table 1

Key Characteristics of the Studies Included

Author	N	Intervention Duration	Outcome Measures	*P*-value	Effect Size
Blackledge and Hayes, 2006	20	14 hours	3-weeks pre-group to 3-months follow up:		
			Depression	$p = 0.06$	
			General psychiatric problems	$p = 0.048$	
			Psychological distress	$p = 0.021$	
			Cognitive fusion	$p = 0.035$	
			Experiential avoidance	$p = 0.043$	
Corti et al., 2018	42	18 hours	At post-test, IG compared to CG:		
			Mindfulness	$p<0.02$	ηp2 = 0.14
			Stress	$p = 0.06$	ηp2 = 0.09
			Cognitive fusion	$p = 0.74$	ηp2 = 0.14
Fung et al., 2018	33	1.5 day and 1 refresher session	Pre- to post-intervention:		
			Valued-living	$p < 0.001$	
			Psychological flexibility	$p = 0.001$	
			Cognitive fusion	$p = 0.01$	
Hahs, et al., 2019	18	4 hours	1-week post-test, IG compared to CG:		
			Experiential avoidance	$p = 0.0318$	$d= 0.94$
			Depression	$p = 0.0239$	$d= -1.01$
			Cognitive fusion	$p = 0.0485$	$d= 0.83$
			Awareness states	$p = 0.007$	$d= 1.29$
			Shame	$p = 0.0052$	$d= -1.37$
			Values	$p = 0.0159$	$d= 1.11$
			Thought suppression	$p = 0.1732$	
			Mindfulness	$p = 0.2506$	
Joekar et al., 2016	24	8 sessions	At post-intervention, IG compared to CG:		
			Experiential avoidance	$p = 0.001$	
			Depression	$p = 0.01$	
			Anxiety	$p = 0.069$	
			Stress	$p = 0.365$	
			Quality of life	$p = 0.071$	

Author	N	Intervention Duration	Outcome Measures	*P*-value	Effect Size
Jogdand and Magar, 2020	30	Not reported	Pre- to post-intervention:		
			Depression	$p = 0.01$	
			Stress	$p = 0.01$	
			Anxiety	$p = 0.01$	
Lobato et al., 2022	36	9 hours	From pre-test to 2-months follow-up:		
			Psychological flexibility	$p = <0.001$	$d= 1.19$
			Perceived stress	$p = <0.001$	$d= 0.66$)
			Psychological distress	$p<0.001$	$d= 1.08$
			Thought suppression	p<0.001	$d= 1.19$)
			From one week pre-and post-intervention:		
			Positive familial interactions	$p<0.001$	$d= 1.384$
			Negative familial interactions	$p<0.001$	$d= -1.422$
Lunsky et al., 2017	33	1 full-day and 2 evening sessions	From pre to post-intervention:		
			Physical health	$p = 0.004$	
			Depressive symptoms	$p < 0.05$	
			Stress	$p = 0.001$	
Marino et al., 2021	20	36 hours	At post-intervention, IG compared to CG:		
			Psychological flexibility	$p < 0.001$	
			Awareness states	$p < 0.001$	
			Personal values	$p < 0.001$	
			Stress	Not reported	
			Perception of their child's behaviours	Not reported	
Poddar et al., 2015	5	10 sessions	Pre- to post-intervention:		
			Anxiety	$p = 0.04$	
			Depression	$p = 0.04$	
			Psychological flexibility	$p = 0.04$	
			Psychological QoL	$p = 0.04$	
			Physical QoL	$p = 0.52$	
			Social QoL	$p = 0.23$	
			Environment QoL	$p = 0.34$	
Saeedifard et al., 2016	30	9 sessions	At post-intervention, IG compared to CG:		
			Resiliency	$p = 0.01$	$\eta2 = 0.74$
Salimi et al., 2019	30	16 hours	At post-intervention, IG compared to CG:		
			Six emotion regulation strategies	$p<0.05$	

Autism Spectrum Disorder (ASD); Behavioural Parent training (BPT); Control Group (CG); Intervention Group (IG); Number of participants (N); Randomized Controlled Trial (RCT).

Clinical Significance

Based on reliable and clinically significant change (RCSC) calculations, Lobato et al. (2022) reported that none of the parents 'deteriorated' from pre- to post-intervention, or pre-intervention to follow-up on measures of psychological flexibility, stress, psychological distress and thought suppression. The percentage of participants who 'improved' or 'recovered' on outcome measures was as follows: on psychological flexibility scores, 63.8%

at post-intervention and 66.6% at follow-up; on stress scores, 36% at post-intervention and 61.1% at follow-up; on psychological distress scores, 25% at post-intervention and 55.5% at follow-up; on thought suppression scores, 52.7% at post-intervention and 58.3% at follow-up.

Assessment of Risk of Bias: Randomised Studies

The quality of four randomised control trials (RCTs) was evaluated using the RoB 2 (Appendix B). For domain one, two studies randomly allocated participants using a computer program, and demographically and clinically matched participants (e.g. on questionnaire scores and background factors) to reduce the risk of bias (Hahs et al., 2019; Marino et al., 2021). However, two studies did not outline the randomisation procedure employed, allocation concealment or any differences between the control and intervention groups (Saeedifard et al., 2016; Salimi et al., 2019). As such, both studies were rated as ‘some concerns’ in the risk of bias arising from the randomisation process.

In domain two, the participants and facilitators in all four studies were aware of the assigned intervention; however there were no deviations from intended interventions and an appropriate analysis was used. On this basis, all RCT studies were rated as ‘low’ risk of bias in domain two. Similarly, all studies were rated as ‘low’ risk of bias in domain three as the outcome data was available for all participants. In all four studies participants informed the outcome measures, which consisted of a low degree of objectivity and were likely to be influenced by participants’ awareness of receiving ACT. Furthermore, two studies used an inactive group control (Saeedifard et al., 2016; Salimi et al., 2019) and therefore did not control for non-specific intervention factors (e.g. participant effort, attention and expectancy). As such, the intervention effects for both studies may have been overemphasized.

Moreover, two studies only utilised one outcome measure, as a consequence it is possible that all of the intervention effects were not measured (Saeedifard et al., 2016; Salimi et al., 2019). All four RCT studies did not collect outcome measure data at follow-up and therefore the longer-term effects of the intervention could not be assessed. For these reasons, all studies were rated as ‘some concerns’ or ‘high’ risk of bias in the measurement of outcome. For domain five, Marino et al. (2021) did not utilise an effect size calculation and therefore it was not possible to assess the size of the difference between the control and intervention groups. Two studies used an ANCOVA or MANCOVA (Saeedifard et al., 2016; Salimi et al., 2019); these statistical tests reduced the risk of a type one error in contrast with the multiple t-tests employed by one study (Hahs et al., 2019). Nevertheless, Salimi reported that ACT had no significant effect on rumination, however the p value was below 0.05 and therefore was in the significant range. One study did not outline the pre-determined statistical analysis plan (Salimi et al., 2019) and therefore was rated as ‘some concerns’ in relation to risk of bias in the selection of the reported result. On this basis, the overall risk of bias ratings were ‘some concerns’ for Hahs et al. (2019) and Marino et al. (2021), and ‘high’ risk for Saeedifard et al. (2016) and Salimi et al. (2019). It is important to note that Garcia et al. (2021) rated the study by Hahs et al. (2019) study using the ROB 2 and their domain-level and overall risk of bias judgements were consistent with the ratings in this review.

Assessment of Risk of Bias: Non-Randomised Studies

The quality of eight non-randomised studies was evaluated using the ROBIN-I (Sterne et al., 2016; Appendix B). For domain one, six studies did not use a control group and therefore did not minimise or account for non-specific intervention factors (e.g. therapeutic rapport, and participant and therapist expectation), and therefore the results obtained cannot be confidently attributed to solely the ACT intervention. On this basis, it is possible that these studies may have overemphasized the effects of the ACT groups. Two studies utilised a control group (Corti et al., 2018; Joekar et al., 2016), but did not randomly allocate participants. Both studies did not match participants based on clinical and/or demographic variables (e.g. outcome measure scores), but statistical analyses revealed no significant differences between intervention and control groups on outcome measures at pre-intervention. Of these two studies, only one study utilised an active control group consisted of weekly individual counselling sessions (Joekar et al., 2016) and therefore adequately controlled for the nonspecific intervention effects such as therapeutic alliance, participant expectancy and levels of attention. Nonetheless, the format of the control (i.e. individual sessions) was different to the intervention group, and therefore may not have controlled for other non-specific effects (e.g. peer support from other family carers). Notably, Corti et al. (2018) did not provide any direct psychological intervention for parents in the control group and therefore did not control for the potential impact of resentful demoralisation and differences in nonspecific treatment factors between groups (e.g. time and attention given to participants). For these reasons, all eight studies were rated as ‘moderate’ risk of bias in domain one.

In domain two, all eight studies were rated as ‘low’ risk of selection bias as all eligible participants were included in the studies and the start of intervention and follow-up coincided for all participants. In domain three, all eight studies clearly defined and recorded the intervention groups at the start of the intervention, and thereby were rated as ‘low’ risk of bias in the classification of interventions. In domain four, there were no deviations from intended interventions and an appropriate analyses were used. In addition to this, the co-intervention provided to the parent’s children in the study by Corti et al. (2018) was balanced between groups. On this basis, all eight studies were rated as ‘low’ risk of bias in domain four. All studies were rated as ‘low’ risk of bias in domain five as the outcome data was available for all or nearly all participants.

In domain six, all eight studies used participant reported outcome measures. Therefore, these measures involved a low degree of objectivity and were likely to be influenced by participants’ awareness of receiving the ACT intervention. One study only utilised one outcome measure (Jogdand and Magar, 2020), and therefore it is possible all of the intervention effects were not measured. Three studies did not collect outcome measures at follow-up (Corti et al., 2018; Jogdand and Magar, 2020; Poddar et al., 2015) and it was not possible to assess the longer-term effects of the intervention. For these reasons, all studies were rated as ‘moderate’ risk of bias in the measurement of outcome.

For domain seven, one study did not outline the statistical analysis plan and therefore was rated as ‘moderate’ risk of bias in the selection of the reported result (Jogdand and Magar, 2000). Only Lobato et al. (2022) calculated changes in outcome measures at individual-levels using RCSC calculations in addition to group-level analyses. Similarly, only two studies calculated the ACT intervention effect size (Corti et al., 2018; Lobato et al., 2022). As such, for the remaining six studies it was not possible to assess the size of the differences in outcome measures between time points. In addition, two studies completed non-parametric statistical tests (Blackledge and Hayes, 2006; Poddar et al., 2015), which have less statistical power than parametric tests. Nevertheless, the remaining seven studies were rated as ‘low’ risk of bias in domain seven. For all eight studies, the overall risk of bias was assessed as ‘moderate’. It is important to note that Garcia et al. (2021) rated five of the eight studies using the ROBINS-I (Blackledge and Hayes, 2006; Corti et al., 2018; Fung et al., 2018; Joekar et al., 2016; Lunsky et al., 2017) and their domain-level and overall risk of bias judgements were consistent with the ratings in this review.

Critical Appraisal

More broadly, the specific ACT qualifications and clinical experiences of the facilitators were not reported in any of the studies; however these factors are likely to have influenced the intervention effects. Two studies used four ACT processes (Poddar et al., 2015; Salimi et al., 2019) and ten studies used all six core ACT processes in their intervention. Nevertheless, one study did not document the ACT processes or protocol implemented (Jogdand and Magar, 2020), hence it was not possible to identify the core therapeutic processes utilised and the subsequent effects on the outcomes. In addition to this, only Blackledge and Hayes (2006) completed a direct assessment of treatment fidelity through the use of video tapes and adherence ratings, and two studies used measures of social validity to determine parents' satisfaction and acceptability of the intervention (Corti et al., 2018; Lunsky et al., 2017). However, for the studies without these measures, the levels of treatment fidelity and social validity and the subsequent effects on outcomes could not be investigated. Only Marino et al. (2021) and Saeedifard et al. (2016) conducted a sample size calculation using a power analysis. Hence, it was possible that the other studies included inadequate sample sizes, undermining the statistical power and the probability of obtaining a significant result. A common strength for all of the studies was the use of standardised, validated and reliable outcomes to measure effectiveness.

Discussion

The purpose of this review was to examine the effects of ACT interventions for family carers of individuals with IDs and/or ASCs across a number of outcome measures. The findings indicated that carers reported improvements in familial interactions, emotion regulation and mental health outcomes, namely resiliency, shame and depression. Moreover, there were improvements in measures of awareness states, values, and psychological flexibility. These findings are supported by three existing reviews (Chua and Shorey, 2021; Garcia et al., 2021; Magnacca et al., 2021). However, mixed findings were reported on measures of anxiety, stress, cognitive fusion, experiential avoidance, mindfulness and quality of life. These inconsistent findings could be explained by the diversity in the risk of bias ratings across studies (Garcia et al., 2021). Importantly, the findings should be interpreted within the context of the studies' risk of bias ratings. For RCTs, the overall risk of bias for RCTs ranged from 'some concerns' to 'high' risk of bias. The overall risk of bias was assessed as 'moderate' for all eight non-randomised studies. Overall, research studies with a lower risk of bias are needed to more accurately evaluate the effectiveness of ACT in this population.

Population

Parents of children and/or adolescents with IDs and/or ASCs were the only family carers included in all articles. Of these, nine of the studies included parents of children with ASCs.

No studies included family carers other than parents (e.g. siblings), or family carers of adults with ASCs or IDs. Despite the lack of research, it has been revealed that supporting adults with IDs and/or ASCs may present with additional challenges (Kruithof et al., 2022). For example, many family carers can experience high levels of stress and anxiety about the future arrangements of their relatives' care and accommodation (Kruithof et al., 2022). Similarly, seven studies only included mothers within their sample and one study did not specify the type of family carer (Lobato et al., 2022). Nevertheless, fathers and siblings have also reported negative experiences and challenges associated with being a carer, which may differ to mothers (Benderix and Sivberg, 2007; Cameron and Cooper, 2021; Kruithof et al., 2022). Future research should evaluate the effects of ACT within these populations.

Additionally, the studies were only conducted in six different countries: Iran, Spain, Italy, Canada, United States, and India. Notably, none of the studies were completed in the UK. Research has revealed that caregivers' experiences and mental health may differ according to culture (Papadopoulos et al., 2019). Additionally, nine studies did not complete a sample size calculation to establish the minimum number of participants required to obtain a significant result. The generalisability of the findings may have been reduced due to sampling bias resulting from small samples and non-probability sampling in all studies (Patel et al., 2003). In future, research should recruit participants according to a sample size calculation, and investigate the effectiveness of ACT across different cultures.

At pre-intervention, there was substantial heterogeneity across articles on participants' outcome measures, demographics, life style and social support. For example, the heterogeneity of outcome measures was related to the range of general and carer specific outcomes used (e.g., parenting stress measures versus general stress measures), which may have affected the results. These factors are reported to moderate the mental health of caregivers, (e.g., Lloyd & Hastings, 2009), and thus may have impacted the findings (see Juvin et al., 2021). Additionally, there is some evidence that individuals with heightened levels of stress prior to the ACT intervention benefit the most (Levin et al., 2017). Future studies should examine the intervention moderators to enhance treatment gains within this population (Mackinnon, 2011).

Intervention

Blackledge and Hayes (2006) were the only study to collect direct measures of treatment integrity, and no studies used questionnaires or scales to measure treatment integrity (see

O’Neill et al., 2019). Consequently, for the remaining eleven studies, it was not possible to determine the relationship between the specific ACT interventions and outcomes (Plumb and Vilardaga, 2010). Moving forward, studies should collect and monitor direct behavioural measures and/or clinician’s ratings of treatment integrity. Based on the social validity data from two studies (Corti et al., 2018; Lunsky et al., 2017), parents found the ACT protocol acceptable and were satisfied with the intervention. Nevertheless, additional research is needed to determine the level of carers’ social acceptability and satisfaction of ACT (Garcia et al., 2021). There was diversity in the length, frequency, ACT processes used, and facilitators’ ACT qualifications and clinical experience across studies; all of which may have influenced the intervention effects (Juvin et al., 2021). Future research should aim to investigate the ACT processes, and duration and frequency of ACT interventions required to achieve to best outcomes for family carers (Garcia et al., 2021).

As only one study examined changes in outcomes using RCSC calculations, further research is required to evaluate the effects of ACT within this population at individual levels. Furthermore, six studies did not utilise a control or comparator, and only Joekar et al. (2016) employed an active control group in the form of direct psychological intervention for parents (Joekar et al., 2016). Therefore, the common therapy factors (e.g. connecting with other carers in similar circumstances) were not controlled for in studies using the single group pretest-posttest designs. Hence, the treatment outcomes for these studies may have been overemphasised in the absence of active controls (Guidi et al., 2018). Future research should improve the reliability of control groups by using active controls (e.g. attention placebo and clinical management controls) in order to accurately examine intervention outcomes (Garcia et al., 2021; Guidi et al., 2018). Finally, all ACT interventions were facilitated face-to-face. In one study, however, it was reported that 89 percent of participants decided not to partake in parent ACT group due to work commitments (Corti et al., 2018). Future research should investigate ways to promote access for family carers. This could be achieved by other modes of delivering ACT such as virtual groups and ACT-based mobile apps (Chua and Shorey, 2021; Järvelä-Reijonen et al., 2020).

Outcome Measures

Participants informed the outcome measures in all studies. Hence, the data was likely to be affected by participants’ awareness of receiving ACT and response biases (Chang et al., 2019); both of which can limit the objectivity of the data obtained. Similarly, Lobato et al. (2022) collected self-reported daily estimations of the frequency of punitive-hostile and supportive-companion behaviours; however the accuracy of these behaviours could have been improved by direct frequency measures. Furthermore, there can be significant improvements in the frequency values-based behaviours per day, but limited changes on participant informed outcome measures (Gould et al., 2018). Future studies should use self-reports in conjunction with other measures (Guidi et al., 2018), for example direct observations of behaviours (see Gould et al., 2018), and bioindicators of inflammation and stress (Järvelä-Reijonen et al., 2020).

Additionally, only five articles measured intervention outcomes at follow-up (Blackledge and Hayes, 2006; Fung et al., 2018; Joekar et al., 2016; Lobato et al., 2022; Lunsky et al., 2017), with a maximum follow-up time of three months (Fung et al., 2018). As a result, it was not possible to assess the long-term impact of the ACT-based interventions. The seven studies without follow-up measures may not have captured all changes in outcomes as some studies have only observed significant improvements at follow-up, with largest effects at six months post-intervention (e.g., Gould et al., 2018). This suggests that some ACT skills require more time to develop (Hartley et al., 2019; Singh et al., 2014). Therefore, future studies should obtain data over longer time points (e.g. six months).

Systematic Literature Review Limitations

This systematic literature review had several methodological limitations. For example, this review only included papers published in English which may have introduced language bias and limited the findings (see Jackson and Kuriyama, 2019). The quality appraisal assessments were completed by one reviewer who had limited experience of using both tools and had not attended any formal training; all of which may have negatively impacted on the accuracy and reliability of the quality assessments (da Costa et al., 2017). In addition to this, some studies have reported low inter-rater reliability in the domain and overall judgement risk of bias ratings between different reviewers on the RoB 2 (Minozzi et al., 2020) and ROBIN-I (Minozzi et al., 2019). Additionally, both risk of bias tools do not assess all potential sources of bias and threats to validity such as conflicts of interest related to researchers and funders (Munder and Barth, 2018; Viswanathan et al., 2018) and publication bias (Cuijpers et al., 2010). As a result, it is possible that other methodological issues and sources of biases in the studies may not have been captured in this review.

Additionally, due to high levels of heterogeneity, the absolute effect of ACT was not calculated using a meta-analysis (Lee, 2019). Moreover, only peer-reviewed articles were included in this review and therefore the results of this review may have been impacted by publication bias (Ayorinde et al., 2020). More specifically, it is possible that the published studies included more positive outcomes than unpublished research on ACT within this population (Polanin et al., 2016). Also, it is plausible that not all of the adults met the diagnostic threshold for ID and/or ASC as the procedures to confirm their diagnosis were not restricted. Lastly, qualitative evidence on the effects and experiences of ACT on family carers was not included in this review (e.g. Reid et al., 2016). Overall, the findings outlined in this review should be interpreted within the context of these limitations.

Conclusion

To conclude, the findings revealed that ACT groups for parents of children and young people diagnosed with ASC and/or ID can significantly improve a range mental health outcomes and ACT processes. The results of this review are supported by comparable systematic reviews. Nevertheless, improvements in the quality of studies are needed to more accurately assess the effects of ACT. Moreover, due to limited follow-up data, it was not possible to make conclusions about the long-term impacts of ACT. The majority of studies did not obtain or monitor measures of social validity and treatment integrity. All studies exclusively employed participant informed outcome measures. Finally, eleven studies used inactive or no control groups and hence did not account for nonspecific intervention effects. In future, researchers should aim to improve the quality of studies, and address the research gaps identified.

Rationale for the Current Research

The design of this research was selected based on the methodological limitations of the studies included in this review and the gaps in the research identified. Specifically, this will be the first known study to examine the effectiveness, feasibility and acceptability of ACT for family carers of adults with IDs. In addition, this research will provide insights into the mental health, wellbeing and quality of life and demographics of this carer population. It is also hoped that this feasibility study will inform future ACT studies and protocols within this population. Additionally, this research will potentially impact the psychological interventions and support offered to family carers both locally and nationally. Lastly, this research will possibly inform local and national policies which are inclusive of family carers of adults with IDs.

Chapter Three: Methods

Chapter Overview

This chapter will outline methodology used for this study. The first section will outline the ontological and epistemological positions adopted. This will be followed by a summary of the research paradigm and design. In the second section, the recruitment strategy, screening process and research setting will be outlined. The third section will describe the ACT intervention, data collection procedures and outcome measures used. This will involve a description of the psychometric properties of the six questionnaires used and measures of family carers' problematic and values-based behaviours. The fourth section will outline the social validity questionnaire, demographic questionnaire and treatment fidelity measures used. The fifth section will summarise the group- and individual-level data analysis plan. This will describe the statistical assumptions checked for inferential tests, non-clinical and clinical norms used for individual-level analyses, feasibility calculations, and sample size calculation. The final section outlines the inclusion and exclusion criteria, ethical considerations and dissemination plan.

Ontological Positioning

The ontological position refers to the way in which the researcher views the nature of reality (Mertens, 2015). Realism and relativism perspectives exist at opposite ends of the ontological continuum (Coolican, 2018). Realism assumes that one reality exists which is external to human understanding (Mertens, 2015). In contrast, relativism assumes that there are multiple constructed realities, which are important in understanding the phenomenon being studied (Coolican, 2018). This study adopted a realist ontological position by assuming that the reality of family carers of adults with ID could be understood by collecting data through the use of objective observations to support or refute a hypothesis (Mertens, 2015). More specifically, this study used objective measurements of family carers' mental health, quality of life, ACT processes and positive aspects of caring to support or refute hypotheses about the effectiveness of an ACT intervention.

Epistemological Positioning

The epistemological position of research relates to the way in which the researcher acquires, communicates and understands the nature of human knowledge (Grix, 2019; Willig, 2013). Positivism and constructivism exist at opposite ends of the epistemological continuum. Positivism adheres to the assumption that knowledge is objective and therefore the data, interpretations and outcomes are independent to researcher and participants (Guba and

Lincoln, 1989). Alternatively, constructivism adheres to the assumption that knowledge is ever changing, subjective and co-created based on the researcher's perspective and participants' individual experience (Creswell and Creswell, 2018). This study adopted a positivist epistemological position whereby group facilitators were expected to follow the same intervention ACT procedures and the participants completed the same standardised outcome measures.

Research Paradigm

The research paradigm selected for this study was based on the assumptions of the ontological and epistemological positions of the researcher (Braun and Clarke, 2013). As such, a quantitative framework was employed as this draws upon a realist ontological position and positivist epistemological position, which are best placed to answer the research question (Coolican, 2018). Quantitative methodology lends itself well to evaluate the effectiveness of psychological interventions by controlling variables, and eliminating and/or minimising the impact of confounding variables (Mertens, 2015). Moreover, the current lack of quantitative research into the effects of ACT on family carers of adults with IDs highlights a gap in the research literature which could be used to identify effective psychological interventions for family carers.

Design

A single group pretest-posttest design was utilised. The independent variable was a six hour ACT workshop. There were ten dependent variables in this study: depression, anxiety and stress symptoms, psychological flexibility, mindful states, cognitive fusion, quality of life, positive aspects of caregiving, and the frequency of problematic and values-directed behaviour. This design was selected for a number of reasons: (a) existing research on ACT with families of children with autism have used group interventions, (b) to give participants the opportunity to meet other family carers, (c) to increase the likelihood of family carers being able to attend the workshop due to time constraints related to caring commitments, (d) to maximise the number of participants recruited within the timeframe of a doctoral thesis, and (e) to minimise participant attrition. In addition, it is important to note a meta-analysis reported that ACT workshops had similar effects to longer-term ACT interventions (see Powers et al., 2009).

The main objective of a feasibility study is to assess the feasibility and acceptability of a study and/or intervention (Abbott, 2014). Alternatively, in effectiveness trials, the primary objective is to assess the effectiveness of an intervention (Abbott, 2014). Feasibility studies have been used in other carer populations (e.g., Kishita et al., 2022) to assess whether or not a full-scale effectiveness trial was deemed suitable. As a feasibility study, the primary objective of this study was to examine the feasibility and acceptability of ACT for family carers of adults with IDs. The secondary objective of this study was to provide preliminary evidence on the effects of the ACT within this carer population.

The ACT intervention protocol for this study was developed and adapted based on ACT books (e.g. Harris, 2019) and previous research. As shown in Appendix C, the protocol included all of the six core processes and was designed based on the feedback provided by a group of family carers on 27th April 2022. A summary of the carer feedback can be found in Appendix D. Both group facilitators and thesis supervisors had the opportunity to review and make amendments to the ACT intervention prior to the protocol being finalised. The plan was to have a maximum of eight family carers in each group and to deliver at least two ACT workshops. However, the maximum number of participants was increased in the third workshop to maximise on participant recruitment within the timeframe of the doctoral thesis.

The workshops lasted for six hours and were facilitated by two Clinical Psychologists who worked in the adult LD service and were registered with the Health and Care Professionals Council. Prior to facilitating the group, both facilitators had completed a three-day training course in Acceptance and Commitment Therapy at the Association for Psychological Therapies and had clinical experience of using ACT with clients.

As noted by Zody (2017), there were some possible threats to the internal and external validity based on this research design. More specifically, one possible threat to the internal validity was that it was not possible to determine if the outcomes of the group were due to the ACT intervention, the relationships and connections formed with other family carers, the facilitators or both. Another possible threat to the internal validity was potential experimenter bias as the facilitators were aware of the study aims and therefore they may have unintentionally influenced the participants. Controls were used to reduce the risk of experimenter bias: (a) the chief investigator did not facilitate the group intervention, (b) two clinical psychologists facilitated the group, (c) the research was overseen by two thesis supervisors, and (d) the outcome measures were based on self-report. One of the thesis supervisors was also a group facilitator, however they were not involved in collecting the outcome data following the workshops. In addition to this, the ACT intervention procedure was highly detailed to increase treatment fidelity and minimise experimenter bias (Drouillard, 2019). One possible threat to the external validity was the selection of participants as family carers who volunteer to attend the workshops may be more open to discuss and explore their difficulties and change their behaviour (Zody, 2017); as a consequence, the sample in this study may not accurately represent the larger family carer population.

Research Procedure

Recruitment Strategy

Family carers of adults with IDs were recruited from an adult LD service. Family carers included any family members (e.g. siblings and grandparents), guardians, or foster parents of any age who had caring responsibilities (Department of Health, 2010). The group facilitators worked within the adult LD service and disseminated the study information within the service. The study leaflet was emailed to clinicians within the service (see Appendix E) and included in the service's staff newsletter. The leaflets were printed and placed around the adult LD service sites. The group facilitators discussed this study at multiple meetings within the service. The group facilitators reviewed the psychology waiting list within the service and made contact with family carers who were potentially eligible. Other clinicians (e.g. community nurses) within the multidisciplinary team liaised with the facilitators and/or chief investigator to discuss family carers they felt may benefit from the ACT group. Clinicians and group facilitators discussed the workshop with family carers they were working with and invited them to attend. The participant or staff member was asked to email one of the group facilitators and/or the chief investigator if they were interested in taking part in the research study.

Screening Process

The group facilitators or the chief investigator emailed or posted the participant information sheet and consent forms to the participants so they could access the information and complete the consent form independently if they chose. In addition, consent forms completed independently or over the phone were returned to the chief investigator via email or postage-paid envelope. After a week, the chief investigator arranged a screening appointment with the participant over the phone or in-person, and asked the participants the screening questions (Appendix F). If the participant did not meet the inclusion and exclusion criteria, the plan was to signpost the participant to another service to meet their needs, however the need for this did not arise. If the participant was eligible and wanted to take part in the research, they had the opportunity to ask any questions and/or receive help with the forms. If the participant was not sure whether they wanted to participate in the study, participants had 72 hours to decide if they wanted to take part. If the participant provided written informed consent, the facilitator completed the outcome measures with the participant during the screening appointment (time point one). The chief investigator and group facilitators informed the participant that they would make contact with the participant using the contact details provided to inform them of the time and date of the group.

Setting

Based on the feedback from a carer's group, participants initially had to option to attend the ACT workshop in-person at one of the adult LD service sites, or virtually using the service's secure video conference software (Microsoft Teams). The first workshop was offered face-to-face at an adult LD service site. However, several participants reported potential barriers to attending the ACT workshop face-to-face (e.g. transport issues and caring commitments). Hence, the remaining two workshops were offered virtually to maximise the number of participants in attendance. Notably, there is evidence to support the delivery of ACT via video conferencing platforms (Lavelle et al., 2022). The plan was to facilitate the group virtually using the service's secure video conference software if the Coronavirus Disease 2019 restrictions were reintroduced, however COVID-19 restrictions were not reinstated during this research study.

ACT Intervention

One week prior to the group, participants were asked to select and define two problematic behaviours they wanted to decrease. Participants were asked to record the daily frequency of these behaviours on a chart over the next four weeks. Based on the feedback from carers, on the day of the workshop, participants had the option to attend the group 30 minutes before the start time to socialise with other family carers and/or to discuss the group. At the start of the workshop, participants were informed of the aims of the workshop, the limits of confidentiality and were told that they had the right to withdraw from the group at any point without providing a reason. During the six hour workshop, the participants were invited to take part in a number of activities, exercises, metaphors and discussions (please see the group protocol for full details of the intervention). At the end of the group, the participants were asked to complete the social validity questionnaire (Appendix G). Participants were invited to attend a debrief session and received a summary of the research findings via email. Lastly, participants were informed that they had the option to stay for another 30 minutes to socialise with other family carers.

Collecting Outcome Measures

The chief investigator offered to complete the outcome measures with participants at time point two (three weeks post-intervention) and time point three (three months follow-up) over the phone or virtually, or to receive and return these via email. If the participants asked for support to complete the outcome measures, the chief investigator arranged a time to contact the participants over the phone to collect the outcome measures three weeks and three months after the group (time points two and three). If participants decided to complete the outcome measures via email, these were emailed over to the participants and an email reminder was sent to participants. If the participants did not complete the outcome measures within a week after the time point (e.g. four weeks after the group), the chief investigator attempted to make contact with the participant over the phone and/or email, and offered to complete the outcomes over the phone and/or prompted them to complete the outcome measures. The group facilitators (Clinical Psychologists) prompted a few participants to complete the outcome measures, but they were not actively involved in the data collection process.

Measures

Six self-reported outcome measures (see Appendix H) were collected at three time points: during the screening appointment (time point one), three weeks after the workshop (time point two), and at three months follow-up (time point three). Three ACT process measures were used to measure the proposed therapeutic mechanisms of change in ACT (Hayes, 2004):

- **Acceptance and Action Questionnaire version II** was used to measure overall psychological flexibility and experiential avoidance (Bond et al., 2011).
- **Cognitive Fusion Questionnaire** was used to measure cognitive fusion (Gillanders et al., 2014).
- **Mindful Attention Awareness Scale** was used to measure mindful states (Brown and Ryan, 2003).

Four outcome measures related to family carers' mental health, quality of life and positive aspects caregiving were used:

- **Depression Anxiety Stress Scales** were used to assess symptoms of depression, anxiety and stress (Henry and Crawford 2005).

- **Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form** was used to measure the levels of enjoyment and satisfaction across various areas of daily functioning (Endicott et al., 1993).
- **Positive Aspects of Caregiving** was used measure the positive aspects of caregiving (Tarlow et al., 2004).

Further details on the outcome measures used are provided below.

Acceptance and Action Questionnaire-II

The Acceptance and Action Questionnaire version II (AAQ-II) was used to measure overall psychological flexibility and experiential avoidance (Bond et al., 2011). The AAQ-II consisted of seven items, each scored between one and seven (1 = never true, 2 = very seldom true, 3 = seldom true, 4 = sometimes true, 5 = frequently true, 6 = almost always true, 7 = always true). The AAQ-II questionnaire was selected as the seven item version of the questionnaire has better psychometric consistency than the AAQ-I (Bond et al., 2011). The AAQ-II has a Cronbach's Alpha levels between 0.78 - 0.88, test-retest reliability between 0.79 – 0.81, and adequate construct validity (Bond et al., 2011). An example item was "I'm afraid of my feelings". AAQ-II scores were calculated by summing the numbers circled from the seven items, with a maximum score of 49 and a minimum score of seven; higher scores represent higher levels of psychological inflexibility and experiential avoidance (Bond et al., 2011). The AAQ-II does not have cut-off scores to indicate when people are likely to meet the criteria for a psychological disorder; however scores above 24 – 28 are associated with clinically relevant levels of psychological distress (Bond et al., 2011).

Cognitive Fusion Questionnaire

The Cognitive Fusion Questionnaire (CFQ) was used to measure cognitive fusion (Gillanders et al., 2014). The CFQ consisted of seven items, each scored between one and seven (1 = never true, 2 = very seldom true, 3 = seldom true, 4 = sometimes true, 5 = frequently true, 6 = almost always true, 7 = always true). An example item was "My thoughts cause me distress or emotional pain". The CFQ has Cronbach's alpha levels between 0.88 – 0.93, test-retest reliability of 0.80, and good construct validity (Gillanders et al., 2014). CFQ scores were calculated by summing the numbers circled from the seven items, with a maximum score of 49 and a minimum score of seven; higher scores represent higher levels of cognitive fusion (Gillanders et al., 2014). The items in the CFQ were developed based on the knowledge and clinical practice of a group of expert ACT clinicians (Gillanders et al., 2014). The CFQ does not have cut-off points to indicate when people are likely to meet the criteria for a psychological disorder; however higher scores are associated with higher levels of distress and burnout (Gillanders et al., 2014), as well as symptoms of depression and anxiety (Luque-Reca et al., 2021).

Mindful Attention Scales

The Mindful Attention Awareness Scale (MAAS) was used to measure mindful states (Brown and Ryan, 2003). The MAAS consisted of 15 items, each scored between one and six (1 = almost always, 2 = very frequently, 3 = somewhat frequently, 4 = somewhat infrequently, 5 = very infrequently, 6 = almost never). The MAAS has a Cronbach’s alpha between 0.80 – 0.92, test-retest reliability of 0.81, and adequate construct validity (Brown and Ryan, 2003). An example item was “I find myself preoccupied with the future or past”. MAAS scores were calculated by summing the numbers circled from the fifteen items, with a maximum score of 90 and a minimum score of 15. Brown and Ryan (2003) averaged the 15 item scores in their original study. However, the total average MAAS score was calculated and used in this study as the largest sample sizes available in the literature for non-clinical and clinical MAAS norms had calculated the total average MAAS scores (Ayhan and Kavak Budak, 2021; Ruiz et al., 2016). Higher scores on the MAAS indicate a higher awareness of internal experiences and overt behaviours (i.e. mindful awareness and attention). The MAAS does not have cut-off scores to indicate when people are likely to meet the criteria for a psychological disorder. Nevertheless, higher scores on the MAAS are positively correlated with emotional wellbeing, self-regulated behaviour and life satisfaction (Brown and Ryan, 2003), and negatively correlated with depression, anxiety and stress (Rayan & Ahmad, 2018).

Depression Anxiety Stress Scales

The Depression Anxiety Stress Scales (DASS-21) was used to measure symptoms of depression, anxiety and stress (Henry and Crawford, 2005). The DASS-21 consisted of 21 items, each scored between zero and three (0 = did not apply to me at all, 1 = applied to me to some degree or some of the time, 2 = applied to me a considerable degree or a good part of time, 3 = applied to me a very much or most of the time). The DASS-21 has a Cronbach’s alpha of 0.88, test-retest reliability between 0.80 – 0.86, and adequate construct validity (Henry and Crawford, 2005; Silva et al., 2016). An example item was “I felt down-hearted and blue”. There are seven items for each depression, anxiety and stress subscale, with a maximum score of 42 and a minimum score of zero. For each subscale, the identified numbers are summed and multiplied by two. Higher scores indicate higher symptoms of depression, anxiety and stress (Henry and Crawford, 2005). The scores for each subscale were used to determine the severity of depression, anxiety and stress based on cut-off scores ranging from normal, mild, moderate, severe, and extremely severe (Henry and Crawford, 2005). The cut-off scores for each DASS-21 subscale score can be found in Appendix I.

Positive Aspects of Caregiving

The Positive Aspects of Caregiving (PAC) was used to measure the positive aspects of caregiving (Tarlow et al., 2004). The PAC consisted of nine items, each scored between one and minus four (1= disagree a lot, 2 = disagree a little, 3 = neither agree nor disagree, 4 = agree a little, 5 = agree a lot, -3 refused and -4 unknown). The PAC has a Cronbach's alpha of 0.89, test-retest reliability between 0.82 – 0.98, and adequate construct validity (Kate et al., 2012; Tarlow et al., 2004). An example item was "Providing help to a [care recipient] has made me feel appreciated". PAC scores were calculated by summing the numbers circled from the nine items, with a maximum score of 45 and a minimum score of nine. Higher scores on the PAC represent more positive caregiving experiences (Tarlow et al., 2004), and are negatively correlated with depression (Hilgeman et al., 2007).

Quality of Life Enjoyment and Satisfaction Questionnaire

The Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF) was used to assess the levels of enjoyment and satisfaction across various areas of daily functioning (Endicott et al., 1993). The Q-LES-Q-SF consisted of 16 items, each scored between one and five (1= very poor, 2 = poor, 3 = fair, 4 = good, 5 = very good). The Q-LES-Q-SF has a Cronbach's alpha between 0.89–0.95, test-retest reliability of 0.93, and adequate construct validity (Hope et al., 2009; Stevanovic, 2011). An example item was "Taking everything into consideration, during the past week how satisfied have you been with your physical health?" Q-LES-Q-SF scores are calculated by summing the numbers circled from the first 14 items, with a maximum score of 70 and a minimum score of 14.

Endicott et al. (1993) suggested converting the total raw score into a percentage maximum score to make comparisons across different aspects of functioning for each participant and within participant groups. The authors recommend using the following formula: raw score minus the minimum raw score divided by the maximum possible raw score minus the minimum raw score. Nevertheless, the total raw score was calculated and used for the data analysis for a number of reasons: (a) this study was not comparing areas of functioning across or within participants, (b) there were no non-clinical norms available for the Q-LES-Q-SF percentage maximum scores, and (c) multiple research studies have used total raw scores (Chen et al., 2017; Hope et al., 2009; Riendeau et al, 2018; Stevanovic, 2011).

The two last items of the Q-LES-Q-SF are considered separately and are not included in the overall score. The Q-LES-Q-SF does not have cut-off points to indicate when people are likely to meet the criteria for a psychological disorder. Nevertheless, higher scores on the Q-LES-Q-SF represent greater perceived quality of life across various areas of daily functioning (Endicott et al., 1993), and are correlated with better self-reported health status (Bourion-Bédès et al., 2015b).

Problematic and Values-Based Behaviours

After screening, participants were sent a worksheet via email or post (Appendix J; Harris, 2019). They were asked to complete this document and operationalise two problematic behaviours to be decreased. One week before the group, participants were asked to record the daily frequency of problematic behaviours over four weeks (up to time point two). An email reminder was sent to the participants one week before the group. During the workshop, participants were asked to operationalise two values-based behaviours and complete a worksheet (Appendix J) to record the frequencies of these behaviours over three weeks (time point two).

Social Validity Questionnaire

A questionnaire was used to collect data on the social validity of the ACT intervention immediately at the end of the session. The group facilitators did not oversee this process or view the responses from the participants. A copy of the social validity questionnaire can be found in Appendix G. This questionnaire was adapted from Wilson et al. (2022) and Kowalkowski (2012) and modified for the purpose of this study. This questionnaire contained nine items. Five items are rated on a five-point Likert scale ranging from one to five (“Not at all” to “A lot”). Higher scores on these five items indicate higher satisfaction with the ACT group (Kowalkowski, 2012), and increased social appropriateness and acceptability of the ACT intervention procedures (Wolf, 1978). Four items were open questions to allow participants to provide feedback on what they most and least liked about the ACT group, how they would change the group and any additional comments or feedback about the group. All anecdotal qualitative feedback was collated into an excel spreadsheet and summarised in the results to ensure that researcher bias was minimised.

Demographic Questionnaire

Participants were asked to complete a 15-item demographic questionnaire (Appendix K). This was designed for this research study to collect demographic information such as age, gender, ethnicity and relationship status.

Treatment Fidelity

The ACT intervention protocol was highly detailed to ensure the facilitators had enough guidance to maintain consistency within and between workshops (Drouillard, 2019). In addition, two methods were used to monitor and measure treatment fidelity. Following each workshop, both group facilitators completed self-reports of the ACT Fidelity Measure (ACT-FM) in collaboration (O'Neill et al., 2019; Appendix L). The ACT-FM consists of 25 items, each scored between zero and three (0 = this behaviour never occurred, one = therapist rarely enacts this behaviour, two = therapist sometimes enacts this behaviour, 3 = therapist consistently enacts this behaviour). The ACT-FM has moderate to excellent inter-rater reliability, which has ranged between 0.60–0.93 (O'Neill et al., 2019). An example item was "Therapist helps the client to notice thoughts as separate experiences from the events they describe". For the consistent or inconsistent ACT scale, the maximum score was 36 and the minimum score was zero. The ACT-FM does not have cut-off points for the consistent and inconsistent ACT scales. However, higher total ACT consistency scores and lower ACT inconsistency scores indicate a higher degree to which the ACT intervention has been delivered as intended (O'Neill et al., 2019). Additionally, in line with previous research by Rauwenhoff et al. (2019), the group facilitators ticked off the exercises completed from the ACT intervention protocol and noted down any exercises added or omitted.

Method of Analysis

Group-Level Analyses

Descriptive Statistics

The data was analysed using Statistical Package for Social Sciences (SPSS) version 28 and Microsoft Excel. A range of descriptive statistics were used to summarise participants' outcome data across time points and demographic information. Frequencies and percentages were calculated for nominal data (e.g. ethnicity and relationship status). Mean and standard deviations were calculated for ratio data (e.g. number of years caring for their relative), including all eight outcome measures across three time points. Frequencies of participants' problematic and values-based behaviours were plotted on a line graph.

Test of Multivariate Normality & Equality of Multiple Variance-Covariance Matrices

Test of multivariate normality

Multivariate normality was assessed with the Mahalanobis distance test, which produced values (called MAH-1 values) for each observation of the outcome measures. The largest value among all measures was compared to the critical value on the chi-square distribution table (see Appendix M) based on an alpha value of 0.01 and the maximum number of outcome variables, which was eight in this analysis. In the chi-square distribution table, the corresponding critical value is 20.09, which is greater than 18.97, the maximum MAH-1 value from the Mahalanobis distance test. Hence, multivariate normality of the data was achieved.

Test of Equality of Multiple Variance-Covariance Matrices

This assumption was assessed with the Box's M Test through Multivariate Analysis of Variance. The text produced a Box's M value of 77.29 and a p-value = 0.908. Since the p-value from the data was greater than 0.001 (i.e., $p>0.001$), the equality of multiple variance-covariance matrices assumption was achieved.

Inferential Statistics

As the data met the parametric test assumptions described above, a one-way within-subjects multivariate analysis of variance (MANOVA) was used to detect any significant differences across three time points. A Bonferroni correction was applied to reduce the risk of a type one error. The plan was to follow-up any significant results from the multivariate analysis with a one-way within-subjects ANOVA for each outcome measure to determine which outcome measure(s) was contributing to the significant result. Additionally, the plan was to follow-up any significant results from the one-way within subjects ANOVA with a Bonferroni post-hoc test to determine where the significant difference(s) were across the time points, for example between time points one and two, two and three, and one and three.

Non-Parametric Tests

A Friedman test was used to detect any significant changes across the three time points when the data did not meet the parametric test assumptions. Any significant results on the Friedman test were followed up by a Wilcoxon signed-rank test to identify the significant difference(s) across the time points, for example between time points one and two, two and three, and one and three. A confidence interval of 95% was used to calculate effect size for all statistical tests.

ACT consistent and inconsistent item scores were analysed to assess treatment fidelity, in line with previous studies (Ong et al., 2019; Villatte et al., 2015; Wicksell et al., 2012). Based on existing research comparing treatment fidelity across sessions (e.g., Villatte et al., 2015), non-parametric tests were completed to detect any significant changes in treatment fidelity across the three ACT workshops. As the treatment fidelity data violated normality tests (i.e. the Kolmogorov-Smirnov and Shapiro-Wilk statistic was significant), a Friedman test was completed on ACT consistent and inconsistent item scores across all three workshops. Finally, a Wilcoxon signed-rank test was completed on the ACT consistent and inconsistent item scores to detect any differences in consistency scores.

Individual Analyses

RCSC was calculated for five self-reported outcome measures, namely the DASS-21, Q-LES-Q-SF, CFQ, AAQ-II, and MAAS. RCSC calculations were not completed for the PAC scores as there was no published clinical or non-clinical norms, or clinical cut-off points. An externally determined cut-off was used for RCSC calculations based on clinical cut-off points on the DASS-21 subscales: ten on the depression subscale, eight on the anxiety subscale and 15 on the stress subscale (Henry and Crawford, 2005). For the RCSC calculations, the reliability of the outcome measures used was based on Cronbach's alpha. The Cronbach's alpha included in the RCSC calculations were selected based on the largest sample size available from the sample norms reviewed in the literature. Based on a non-clinical sample of 1,794 adults from the general UK population (Henry and Crawford, 2005), the Cronbach's Alpha values of 0.88 was used for the depression subscale, 0.82 for the anxiety subscale and 0.90 for the stress subscale.

The Jacobson-Truax (Jacobson and Truax, 1991) method was used to evaluate the clinical significance of the ACT intervention effects at an individual level for the remaining four outcome measures aforementioned. This method was used to determine the number of participants who achieved reliable and clinically significant change on outcome measures between time points one and two, and time points one and three, which could not be attributed to measurement error (Jacobson and Truax, 1991). As advised by Hsu (1996), the criterion "C" was used as the cut-off. The reliable change index and clinical significance change score was calculated using the Leeds Reliable Change Indicator calculator (Morley and Dowzer, 2014).

The participants included in this sample would not be categorised as a clinical or non-clinical population as family carers report higher levels of distress and mental health difficulties than the general population (e.g., Emerson, 2003; Totsika et al., 2011). On this basis, sample norms were selected based on the sample most similar to the sample in this study (e.g. based on gender and age) to the best of the author's knowledge.

Q-LES-Q-SF Norms

For the Q-LES-Q-SF, non-clinical sample norms (*M* = 48.91, *SD* = 7.06) were taken from Chen et al. (2017) based on a sample of 1,957 undergraduate students. This non-clinical sample was selected as no other published non-clinical means and standard deviations were available in the literature. There were published clinical norms available for veterans who had accessed a veterans' mental health clinic (Riendeau et al, 2018), adult outpatients with a mental health diagnosis (Stevanovic, 2011), and adult outpatients with a substance dependence diagnosis (Bourion-Bédès et al., 2015a). However, the clinical sample norms (*M* = 32.29, *SD* = 16.13) were taken from Hope et al. (2009) based on a sample of 1,276 adult inpatients. This clinical sample was used as (a) Hope et al. (2009) had a higher proportion of females included and therefore was more likely to reflect this population, and (b) none of the samples included in this study reported any problems with substance abuse and/or dependence. The Cronbach's alpha 0.86 was taken from Wyrwich et al. (2009).

CFQ Norms

For the CFQ, non-clinical sample norms (*M* = 22.28, *SD* = 8.3) were taken from Gillanders et al. (2014) based on a student and community sample (*n* = 1,040) in the UK (associates of the researcher). Published non-clinical norms were also available for another sample of UK students (Bolderston et al., 2019), German university students and clinicians (China et al., 2018), French university students (Dionne et al., 2016), Hispanic college students (Flynn et al., 2018), and the general population in Brazil (José Quintero et al., 2022). However, these sample sizes were significantly smaller and/or were not based in the UK, and therefore were not selected for the calculation.

The clinical sample norms (*M* = 34.31, *SD* = 8.06) were also taken from Gillanders et al. (2014) based on a mixed mental health sample of 215 participants across the UK (patients who had a confirmed mental health diagnosis). This clinical sample norm was selected as the sample was based in the UK and included a higher proportion of females, and therefore were more likely to reflect the sample included. Published clinical norms were available for a sample of German adult inpatients with a mental health diagnosis (China et al., 2018), Canadian veterans who were struggling with emotional and interpersonal difficulties (Cox et al., 2018), and adult outpatients based in England who were experiencing psychosis (Johns et al., 2016). The Cronbach's alpha of 0.9 was taken from Gillanders et al. (2014).

MAAS Norms

For the MAAS, published non-clinical norms were available for Chinese undergraduates (Deng et al., 2012), Turkish school teachers and white-collar workers (Catak, 2012), American undergraduates (Brown and Ryan, 2003; Gilbert and Christopher, 2010; MacKillop and Anderson, 2007), and college students and the general population from Spain and Portugal (Barajas and Garra, 2014; Elices et al., 2019; Gregório and Pinto-Gouveia, 2013). However, non-clinical sample norms (M = 63.33, SD = 16.17) were taken from Ruiz et al. (2016) based on 762 Colombian undergraduates. This non-clinical sample norm was selected as it was the largest sample of clinical participants available in the literature and was similar to this sample based on gender.

Published clinical norms were available for a sample of outpatients with first-episode psychosis (González-Blanch et al., 2022), Spanish outpatients diagnosed with anxiety, depression or borderline personality disorder (Barajas and Garra, 2014), Spanish inpatients diagnosed with cocaine dependence, borderline personality disorder, or an eating disorder (Elices et al., 2019). The clinical sample norms (M = 32.59, SD = 8.55) were taken from Ayhan and Kavak Budak (2021) based on a sample of 700 adult outpatients diagnosed with depression. This clinical sample norm was selected as it was the largest sample of clinical participants available in the literature and was the most similar to this sample based on age. The Cronbach's alpha 0.92 was taken from Ruiz et al. (2016).

AAQ-II Norms

For the AAQ-II, non-clinical sample norms (M = 19.33, SD = 8.63) were taken from a community sample (n = 884) in Hungary (Eisenbeck and Szabó-Bartha, 2018). Published non-clinical norms were available for a sample of employees from a UK bank (Bond et al., 2011), Portuguese general population (Costa et al., 2014), healthy volunteers from Turkey (Yavuz et al., 2016), and a Greek student and community sample (Karekla et al., 2017). However, these sample sizes were smaller and the proportion of females was lower, and therefore was less likely to reflect this population.

The clinical sample norms (*M* = 40.72, *SD* = 8.59) were taken from a sample of 372 Dutch outpatients diagnosed with mild to moderate depression and anxiety (Fledderus et al., 2012). Published clinical norms were available for a sample of Greek adult outpatients with a mental health diagnosis (Karekla et al., 2017), Turkish adult outpatients who had at least one mental health disorder diagnosis (Yavuz et al., 2016), adult outpatients seeking therapy for substance misuse (Bond et al., 2011), adult outpatients based in England who were experiencing psychosis (Johns et al., 2016), and American veterans exposed to trauma (Meyer et al., 2013). The clinical sample norm was taken from Fledderus et al. (2012) as their participants were the most similar to this sample based on age and gender, and therefore was more likely to reflect this population. The Cronbach's alpha 0.90 was taken from Eisenbeck and Szabó-Bartha (2018). As shown in Table 2, criterion 'C' was used as the cut-off for these four outcome measures.

Table 2

Criterion C used for CFQ, AAQ-II, MAAS and Q-LES-Q-SF

Outcome Measures	Criterion C
Q-LES-Q-SF	43.85
CFQ	28.38
AAQ-II	30.05
MAAS	43.22

The reliable change index values were used to categorise participants. The frequency and percentage of participants in each category was calculated. Participants were classified as: (a) *recovered,* if they moved reliably into the normal range; (b) *improved,* if they have made a positive reliable change but are still in the dysfunctional range; (c) *unchanged,* if they have not made a reliable change; and (d) *deteriorated,* if they made a negative reliable change (Ronk et al., 2013). Participants who 'recovered' and demonstrated a significant improvement, met the threshold for clinically significant change (CSC). The percentage of participants who met the CSC criteria was based on the number of participants in the clinical range at baseline. This was calculated manually as the Leeds calculator includes participants in non-clinical range in the CSC calculation.

Feasibility

Lastly, based on a study by Fowler et al. (2021), the feasibility of the ACT group was measured by calculating the percentage of eligible participants who enrolled, completed the intervention, dropped-out, and completed the outcome measures from time points one to three. The percentage of eligible participants who enrolled was calculated by the number of potential participants who were approached and agreed to be screened for eligibility. This feasibility criteria was developed by Fowler et al. (2021) to examine the feasibility of ACT for caregivers of adults with Alzheimer's disease and related dementias. Therefore, this feasibility criteria was selected as it had been previously used in a comparable feasibility study. Based on the feasibility criteria used by Fowler et al. (2021), the ACT intervention for family carers of adults with IDs was deemed feasible if (a) at least 50% of eligible participants enrolled in the group, (b) at least 70% of enrolled participants completed the whole workshop, (c) at least 70% of enrolled participants completed the outcome measures from time points one to three and (d) at least 70% of enrolled participants reported their overall satisfaction with the ACT group being "a good amount" to "a lot".

Sample Size Calculation

A sample size calculation was completed using G*Power analysis based on a MANOVA repeated measures, within factors. With alpha = 0.05, power = 0.8, one group, three measurements, correlation among repeated measures = 0.5, the projected sample size required for a large effect (f = 0.4) would be approximately 14 participants. A large effect size was used for this calculation based on the effect sizes reported in the systematic literature review (chapter two). To allow for a 15% dropout rate, the aim was to recruit a minimum of 16 participants. Participants from the same or different family were able to attend the workshops.

Exclusion and Inclusion Criteria

Participants were included if they met all of the following inclusion criteria: (1) they were a family carer or guardian of an adult diagnosed with a ID who was under the care of the adult LD service (2) experiencing stress related to their carer-giving role (3), aged at least 18 years old and (4) proficient in English. The plan was to assess the inclusion of participants with special communication needs on an individual basis and to make reasonable adjustments to the group materials and discussions (e.g. using larger fonts, key words, and pictures) if possible. However, if it was not possible to adjust the group/study materials to meet the needs of the participant, the plan was for the chief investigator and group facilitators to signpost the individual to other services which could provide support. Nevertheless, the need for reasonable adjustments did not arise as all participants reported that they were proficient in English and did not report any issues with reading comprehension.

Participants were excluded if (1) they were a non-family member, (2) they had previous experience of ACT, (3) were receiving any other psychological interventions, (4) had changes to their psychotropic medication, (5) had major physical health issues, (6) evidence of substance abuse and/or dependence, (7) psychosis or suicidal ideation, or (8) there was a current safeguarding issue relating to the family. A non-substantial ethics amendment was made to change one of the exclusion criteria (see the next section).

Ethical Considerations

Ethical Approval

Methods were taken to reduce the risk of any ethical issues. This study was conducted in line with the British Psychological Society Code of Ethics and Conduct (2018) and Code of Human Research Ethics (2021). Ethical approval was obtained from the Health Research Authority (Appendix N) and NHS Research Ethics Committee (NHS REC reference: 22/WM/0249; IRAS project ID: 316039; Appendix O). After the study received HRA and Health and Care Research Wales (HCRW) approval, the Research and Development office within the NHS trust provided permission to complete this study within the service (Appendix P), and confirmed capacity and capability to host the study. Lastly, the study was approved by the University of Essex Ethics Research Governance Team (Appendix Q). As mentioned above, a non-substantial amendment was approved to include family carers who were taking psychotropic medication.

The initial plan was to exclude family carers who were taking any psychotropic medication. However, several carers who were experiencing carer-related stress asked to participate, but were excluded due to taking long-term medication (e.g. antidepressants). Subsequently, a non-substantial ethics amendment was granted by HRA NHS REC to include family carers who were taking psychotropic medication. A copy of the NHS ethics amendment email confirmation can be found in Appendix R. The amendment confirmation email was shared with the Research and Development office within the NHS trust, and the Research and Development office department confirmed via email that the amendment could be implemented (Appendix S). The ethical approval granted by HRA NHS REC was accepted by the University of Essex REO Research Governance Team (Appendix T) and a full application for ethical approval was not required through the university's ethics review process.

Informed Consent and Right to Withdraw

Based on previous research (Blackledge and Hayes, 2006), the intervention was presented as 'Acceptance and Commitment Training' rather than 'Therapy' as the intervention was manualised. The consent form was developed to include information about how participant data was stored, used and disposed of, and for the research team to have a record of informed consent. The participant information sheet was developed to provide information about the aims, procedures, and the potential benefits and disadvantages of participation, and the planned strategy of dissemination (see Appendix U). This information was included to enable participants to make an informed decision about whether or not to participate in this research study. Participants were given copies of the study leaflet and participant information sheet prior to their screening appointment, so they had the opportunity to ask the facilitator or chief investigator questions prior to providing informed consent (see Appendix V). Consent forms were sent via email or posted to family carers, and a self-addressed stamped envelope was provided where required. Participants were required to provide written informed consent for the participation and publication of the study. Participants were informed of their right to decline to participate or answer any questions, and to withdraw at any time without giving a reason. Participants were informed that this would not affect the NHS services that their family member received. If they withdrew from the study, any data collected prior to dissemination was deleted. If publications or reports had already been disseminated, these could not be withdrawn, however, these only contained anonymised and aggregated data.

Risk

The participants were not recruited from a clinical sample, however it was possible some participants were experiencing psychological distress associated with their caregiving role (Poddar et al., 2015). It was also possible that exploring and discussing the challenges and experiences of being a family carer during the study was emotionally difficult for participants. After the screening process, all participants were provided with the telephone number for the Samaritans helpline and advised to contact them in the event of any urgent mental health difficulties. In addition to this, participants were advised to contact their GP if they experienced any difficulties in relation to their physical and/or mental health. If required, the facilitators had planned to sign-post participants to any additional services (e.g. mental health services); however the need for this did not arise. In the event of a participant in the online group becoming distressed and ending the video call, the facilitator had planned to contact the participant via email and/or telephone to check-in; however the need for this did not arise. A risk assessment was developed by the chief investigator and signed-off by both thesis supervisors. This risk assessment was used by the facilitators and chief investigator during the study to identify the potential hazardous events/consequences and to implement the current controls and additional controls.

Confidentiality and Anonymity

All information obtained from participants was kept confidential and was not disclosed unless required by law. Prior to the screening process, the limits of confidentiality were explained to the participants as well as safeguarding procedures. At the start of the group, all participants were asked to keep all information shared within the group confidential. Participants were given unique codes to use for the outcome measures. Participants were asked to complete the social validity measures anonymously to increase the likelihood of participants responding to the questions honestly (Audette et al., 2020).

Data Management

All documents with personally identifiable and/or confidential data were stored in a locked filing cabinet within the adult LD service, which only the intervention facilitators and chief investigator were able to access. Participant data was entered and analysed using an SPSS and excel database, which was stored on password protected NHS laptop kept by the researcher. University computers were used to analyse anonymised data on SPSS. At the end of the study, participants were thanked for their participation. All hardcopies of participant documents were disposed of using the confidential waste containers within the adult LD service, and electronic copies were deleted. All participant data was used and stored in accordance with the regulations of the University of Essex and the Data Protection Act 2018.

Debriefing

All participants were invited via email to attend an optional debrief session virtually using Microsoft Teams. A debrief session was used to provide participants with the opportunity to share their reflections, experiences or any issues.

Dissemination

There are plans to disseminate the findings of this research in a number of ways. All participants received a written summary of the findings via email (Appendix W). The final research manuscript will be submitted to the University of Essex and subsequently uploaded onto the University of Essex research repository. Based on similar research (e.g. Gould et al., 2018), the research report will be submitted for publication in a peer-reviewed journal such as the Journal of Contextual Behavioral Science, as well as the Bulletin of the Faculty for People with IDs. Additionally, the research findings will be presented at the area management team and positive behaviour support steering group meetings, and disseminated within the service via the staff newsletter. The research findings were presented at the University of Essex Staff-Student Research Conference. The author will also aim to present the research findings at a conference. Additionally, the findings of this research will be submitted to the Association for Contextual Behavioural Science website to be included in their publications webpage. Lastly, this research will be disseminated through academic social networks such as Research Gate.

Chapter Four: Results

Chapter Overview

This chapter will present the results from data collected and analysed from a one-day ACT workshop for family carers of adults diagnosed with ID. The first section will summarise the descriptive statistics of family carers' demographic information. The second section will outline the feasibility and fidelity of the ACT intervention. In the third section, the quantitative and qualitative data related to the social validity of the intervention will be summarised. The fourth section will include an interpretation of the analyses conducted at group- and individual-levels on six outcome measures across three time points. The chapter will end with a summary of values-based and problematic behaviours reported by the participants from pre- to post-intervention.

Demographics

Twelve females (75%) and four males (25%) completed the study from baseline to time point two. The family carers' ages ranged from 50 to 75 years old, with an average age of 61 years old (*SD*= ± 5.72 years*)*. There were two couples who attended the workshop. The participants' demographic information are presented in Table 3.

Table 3

Frequencies and Percentages of Participant Demographics

	N	%
Occupational Areas		
Retired	5	31.25
Healthcare Worker	5	31.25
Unpaid carer	2	12.5
Administration	2	12.5
Social Care Worker	1	6.25
Police	1	6.25
Ethnicity		
White-British	14	87.5
White-Other	1	6.25
Black-British	1	6.25
Relationship status		
Married	11	68.75
Single/divorced	3	18.75
In a relationship	2	12.5
Relationship with adult diagnosed with an ID		
Mother	10	62.5
Father	3	18.75
Sister	2	12.5
Brother-in-law	1	6.25

11 carers (68.75%) reported that they had not received therapy in relation to carer related stress. Of the five carers who had received therapy, one carer reported that they had received hypnotherapy (6.25%) and three carers reported that they had received counselling (18.75%). Another carer reported that they had accessed an aromatherapy group and individual psychotherapy (6.25%), but did not specify the therapy modality.

Three carers were taking psychotropic medication from time points one and three. Of these, one participant was taking an antidepressant medication on a daily basis, alongside a medication for anxiety when required. This participant had been taking both medications for many years; however there was a recent increase in their antidepressant medication before their screening appointment. The other participant had been taking a medication for anxiety and low mood on a daily basis for the past two years. Another participant was taking anti-depressant medication for a physical health condition. Notably, there were no changes to both participant's medication during the ACT intervention and data collection timeframe.

The age of participants' relative with an ID ranged from 18 to 60 years, with an average age of 32 years old (*SD*= ± 14.43 years). As shown in Table 4, all family carers stated that their relative had received another diagnosis in addition to their ID diagnosis, with the most common diagnosis being ASC.

Table 4

Co-existing Diagnosis for the Identified Adult with ID in Each Family

	N	%
Neurodiversity/Developmental Condition		
Autism	10	62.5
Downs Syndrome	3	18.75
Awaiting ADHD Assessment	1	6.25
Dyslexia	3	18.75
Coffin-Siris Syndrome	1	6.25
Tourette's Syndrome	1	6.25
Sensory Processing Disorder	2	12.5
Dyspraxia	1	6.25
Semantic and pragmatic language disorder	1	6.25
Mental Health Diagnosis		
OCD	2	12.5
Generalised Anxiety	5	31.25
PTSD/Trauma	3	18.75
Neurological Condition		
Acquired Brain Injury	1	6.25
Alzheimer's Disease	1	6.25
Epilepsy	3	18.75
Spinal Cord Injury	1	6.25

As shown in Table 5, the majority of relatives diagnosed with ID were living within their family home (68.75%). All participants were providing social, emotional and practical support for their relative diagnosed with ID (100%), and 13 participants were the joint or sole primary carer (81.25%).

Table 5

Living Arrangements and Family Support for the Identified Adult with ID in Each Family

	N	%
Living arrangements for their relative with an ID		
Family home	11	68.75
Residential care home	2	12.5
Own residence with support from carers	2	12.5
Supported living	1	6.25
Support provided by family carer		
Social	16	100
Emotional	16	100
Practical	16	100
Financial	15	93.75
Family carers who identified as a primary carer for their relative with an ID		
Sole Primary Carer	9	56.25
Joint Primary Carer	4	25
No	3	18.75

The number of hours of support family carers provided per day to their relative diagnosed with ID ranged from one hour to 23 hours, with a mean of 10.3 hours per day. Many carers described feeling as though they were "on call" 24 hours of the day to ensure they were being responsive and meeting the needs of their relative with an ID. Additionally, many carers reported that the level of care they have provided had varied over their relative's life span. 11 carers reported that they had been providing support to their relative since birth. The number of years family carers had provided support to their relative diagnosed with an ID ranged from four years to 60 years, with a mean of 26 years.

Three ACT workshops were facilitated. The initial workshop did not go ahead as seven of the eight participants dropped-out the day before the workshop was scheduled; these participants were invited to attend future workshops. Two participants attended the first ACT workshop face-to-face. 13 participants attended the second workshop, which was held virtually to maximise the number of participants in attendance. However, four participants in the second group dropped out between the workshop and time point two. Five participants attended the third group virtually.

Feasibility

Based on the feasibility criteria used by Fowler et al. (2021), the ACT workshop for family carers of adults with IDs was deemed feasible if all the following feasibility criteria were met:

- At least 50% of eligible participants enrolled in the group.
- At least 70% of enrolled participants completed the whole workshop.
- At least 70% of enrolled participants completed the outcome measures from time points one to three.
- At least 70% of enrolled participants reported their overall satisfaction with the ACT group being “a good amount” to “a lot”.

As shown in Figure 4, 96 family carers were invited via email and/or in-person to participate in the ACT intervention over a 25-week period. 13 caregivers did not reply to the verbal or email invite (13.54%) and 24 participants were not able to attend due to caring or work commitments (25%). 35 participants attended screening appointments. Of these, one (2.86%) was not eligible to participate as they were receiving ongoing therapy. 32 participants completed the questionnaires at baseline and enrolled (33.3%). 20 participants attended the ACT workshop.

In line with Fowler et al. (2021), the first feasibility criteria for at least 50% of eligible participants to enrol in the group was met as the remaining 32 eligible participants (91.43%) provided informed consent and enrolled in the intervention. Two participants withdrew between the screening appointment and workshop (6.25%). On the day of the workshop, ten participants did not attend due to a range of personal circumstances (31.25%).

The second feasibility criteria for at least 70% of enrolled participants to complete the whole workshop was not met as the remaining 20 participants (62.5%) out of the 32 enrolled participants completed the ACT workshop. Four participants withdrew between the workshop and time point two (20%).

The third feasibility criteria for at least 70% of enrolled participants to complete the outcome measures from time points one to three was not met as 15 participants (46.88%) completed the outcome measures from time points one to three.

The fourth feasibility criteria for at least 70% of enrolled participants to report their overall satisfaction with the ACT group being "a good amount" to " a lot" was met as 90.9% of family carers reported the ACT workshop being "a good amount" to " a lot" in terms of their satisfaction.

As shown in Table 6, overall the ACT workshop for family carers would not be deemed feasible as two of the four feasibility criteria were not met.

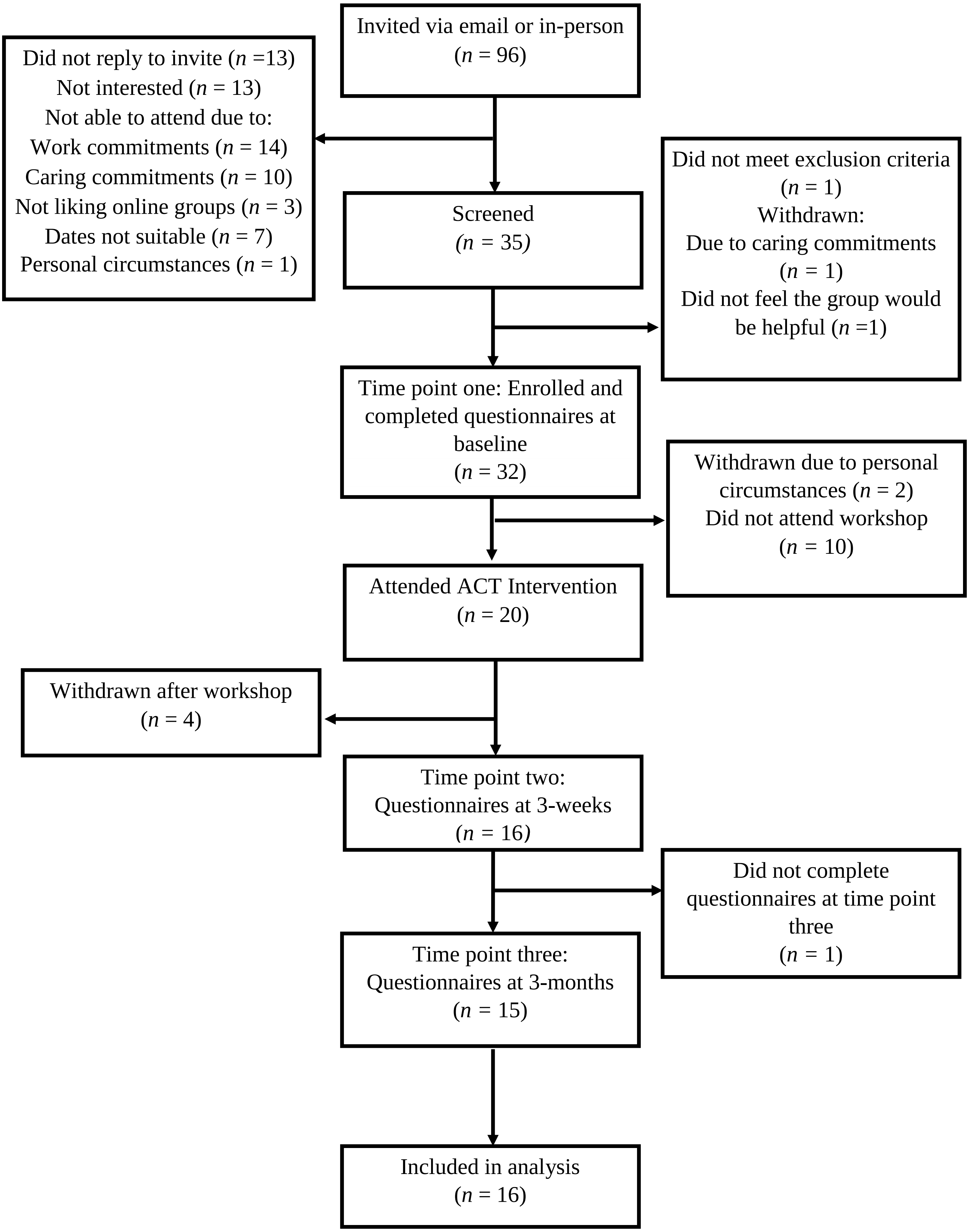
Table 6

Feasibility Criteria and Findings

Feasibility Criteria	Criteria Met (✓/✗)
At least 50% of eligible participants enrolled in the group.	✓
At least 70% of enrolled participants completed the whole workshop.	✗
At least 70% of enrolled participants completed the outcome measures from time point one to time point three.	✗
At least 70% of enrolled participants reported their overall satisfaction with the ACT group being "a good amount" to "a lot".	✓

Figure 4

Participant Enrolment, Screening and Drop-Out



Therapy Adaptations

Three carers indicated that they would be supporting their relative diagnosed with an ID on the day of the workshop. To enable caregivers to still attend the intervention and be responsive to their family members, it was agreed that the caregivers would be able to step away from the virtual workshop at any time when needed. Similarly, on the day of the workshop, two participants had to leave the intervention early and one carer joined the session late due to caring commitments. However, these caregivers were provided with the materials and content required to complete the exercises individually, and the facilitators followed up the caregivers to answer any questions or queries.

Treatment Fidelity

The facilitators completed self-reports of fidelity across the three workshops using the ACT-FM. The ACT consistent and inconsistent scores violated normality tests (i.e. the Kolmogorov-Smirnov and Shapiro-Wilk statistic was significant), and therefore non-parametric tests were used. The SPSS statistic tables for the non-parametric tests below can be found in Appendix X. A Friedman test revealed that there was no significant difference in ACT consistent scores across the three workshops: $\chi 2$ (2, N = 13) = 3.429, $p = 0.180$. Moreover, a Friedman test revealed that there was no significant difference in ACT inconsistent scores across the three workshops: $\chi 2$ (2, N = 12) = 1.2, $p = 0.549$. Further analysis using a Wilcoxon sign-ranked test revealed that there was a significant difference between the ACT consistent (frequencies: *M*= 2.47; *SD*± 0.56) and ACT inconsistent scores (frequencies: *M*= 0.167; *SD*± 0.38) (Z= -5.297; p < 0.01).

As shown in Table 7, the average ACT consistency scores were significantly higher than the ACT inconsistent scores across all subscales. The total average ACT consistent score was 29.3 (out of a maximum score of 35), suggesting that the facilitators' behaviours were highly consistent with the ACT approach (O'Neill et al., 2019). Moreover, the facilitators ticked off the exercises completed from the ACT intervention protocol, and no exercises were omitted or added. Taken together, this data indicates that there was a high degree of adherence and the intervention was delivered as intended.

Table 7

ACT Consistent and Inconsistent Average Subscale Scores on ACT-FM

ACT Consistent	Average Score	ACT Inconsistent	Average Score
Stance	8.0	Stance	1
Open response style	6.3	Open response style	0
Aware response style	7.7	Aware response style	0.3
Engaged response style	7.3	Engaged response style	0
Total Score	29.3	Total Score	1.3

Social Validity

Ten participants completed the social validity questionnaire. One participant completed a social validity questionnaire on the day of the workshop and seven weeks post-intervention to provide further feedback. In total, 11 social validity questionnaires were collected and analysed.

Quantitative Feedback

Five items on the social validity questionnaire were rated on a four-point Likert scale ranging from one to four (where 1 = “Not at all”, 2 = “Sometimes”, 3 = “Often”, 4 = “A lot”). As shown in Table 8, none of the eleven participants responded “not at all” on any of the five items and all responses ranged between “sometimes/somewhat”, “often/a good amount” or “a lot”. The average total score on the social validity questionnaire was 16.4, and the total scores ranged between 13 and 19 (with higher scores indicating higher satisfaction and social acceptability).

Table 8

Frequencies and Percentages of Participant's Responses by Item the on Social Validity Questionnaire

	Not at all	Sometimes/ Somewhat	Often/ A good amount	A lot
How much did you enjoy the ACT activities?	0 (0%)	0 (0%)	6 (55%)	5 (45%)
How much did you learn by doing the ACT activities?	0 (0%)	2 (18%)	3 (27%)	6 (55%)
How much did you learn about thoughts and feelings?	0 (0%)	1 (9%)	7 (64%)	3 (27%)
How often do you plan to use the ideas/skills you learned in the ACT activities?	0 (0%)	2 (18%)	8 (73%)	1 (9%)
Overall how satisfied were you with the ACT group?	0 (0%)	1 (9%)	3 (27%)	7 (64%)

Qualitative Feedback

What did participants most like about the ACT group?

Four items on the social validity questionnaire were open questions to allow participants to provide qualitative feedback and inform future interventions. All ten participants provided examples of what they most liked about the intervention. Six participants commented that they most liked the facilitators of the workshops. Of these, participants reported the facilitators were "very respectful", "kind", "excellent", "very skilled", "personable and friendly", "gave space to think/ask questions", and made them feel "welcome and valued". Importantly, one participant spoke about finding the workshop "a safe, accepting space to share thoughts and feelings with others who understand", and another said they "felt safe to share their experiences and learn from each other". Similarly, one participant said they valued the "chance to talk candidly about feelings". Two participants said they most liked the defusion techniques. For example, one participant commented "changing the language is something that has had an immediate positive impact for both myself and those around me".

Four participants commented on most liking the group format and benefiting from meeting, sharing and/or hearing other carer's experiences. For example, one participant stated "I felt that the group shared a genuine and deep understanding of what it means to be a carer and the acceptance I felt from it and toward the other parents/carers enabled me to consider and hopefully change my attitude towards myself differently". One participant stated that they valued that "all participants had commonalities/struggles". Another participant stated that it was "a nice sized group for a team's meeting". Two participants commented that they most liked learning new coping skills, and one participant most liked "being challenged to address issues and how to cope going forward". Four participants spoke about most liking the videos presented in the workshop. Two participants stated that they found the exercises and techniques useful. Lastly, one participant stated that they most liked the mindfulness tools and another stated that they found the sky and weather metaphor helpful.

What participants least liked about the ACT group?

Two participants commented that it was a lot of information to take in during a one day workshop, and another suggested that "Two half days may be better". Similarly, two participants commented that they would have liked more time to discuss and/or share stories. One participant said "they needed more time to practise coping exercises or given the chance to try before attending the group". Another participant said that the "expansion exercise video was too brief". Two participants commented that they would prefer to do the workshop face-to-face. One participant said "it was a shame there were not more participants". Two carers spoke about having caring responsibilities at the time of workshop and this being a challenge, and of these, one commented that "it is not possible to make the most of the course and still have caring responsibilities happening at the same time". One participant commented "I don't think the concepts will change the way I am doing things". One participant commented that they least liked "some of the exercises", but did not specify which ones. Another stated that "what was required of us in some of the exercises was also not always clear. "This was particularly evident in the last values exercise and in the problem behaviours". Similarly, another participant commented that the values exercise "could be reconsidered". Lastly, one participant said that they "found the style of learning difficult".

What participants would do differently or change about the ACT group?

Four participants stated that they would have liked two shorter sessions" and "longer for carers to interact with each other and share stories". Two participants commented that they would have liked more sessions. Two participants suggested the inclusion of more diverse participants, and this “might have brought in more views. For example, the great majority of carers’ children in this group were aged between 18 and 30, and therefore issues that arise as parents and their children become older were not so much covered”. One participant suggested that they would have liked “more information as to what was expected from the workshop so we could have some time to think before the session”. Four participants stated that they would have preferred a face-to-face group. Of these, one felt this would allow for more “meaningful interaction amongst the participants” and another commented that “it would be easier to connect the learning to some of those real-life feelings and experiences being spoken about”. Similarly, one participant commented “meeting in person and with more participants as I think it would have enabled parents/carers who often feel so isolated to discuss progress, share ideas, offer ongoing support and spur each other on.” One participant suggested “more breakout groups”. One participant commented that they would have liked guidance on understanding and supporting their family member with IDs who was displaying obsessions and compulsions. Finally, one participant suggested that it would be helpful to have more breaks away from the computer.

Additional Feedback or Comments about the group

Four participants said thank you for having the opportunity to attend the workshop. Three participants commented that they would like to attend a group for carers in the future to meet people in similar situations, to “keep everyone engaged and focused on practising the concepts and ideas learnt”, and “to know from a carer’s point of view that others are struggling too”. One participant said it was “Good to be a part of the project. I picked up a lot of good tips”. One participant commented “the actual skills being presented were good”. One participant said “I really enjoyed the group and am sure that I will use at least some of the tools to help me ACT”. Lastly, one participant commented “I am so pleased that carers’ needs and challenges are being recognised and I hope this opportunity will be offered widely to other carers who I feel are so often undervalued and overlooked in society. I’m sure it will benefit both the carer and in turn the cared for person. In particular I think this would be very useful to carers of children who may be struggling to adjust and accept their new life as a carer, as is something that I’m sure would have saved me a lot of pain and unnecessary mental suffering when my child was young, and I started my initially reluctant journey into the world of disability as a carer to my son”.

One participant provided additional feedback seven weeks after attending the workshop and commented “I found the day fun and eye opening, and it had a good balance of presentation and practical elements”. This participant went onto describe that “after trying to do some of the exercises I gave up” as the effects of some of the exercises “did not last” and resulted in them “worrying about exactly the same things as always”, including thoughts about the future welfare of their daughter. This last comment and comments from two other participants on the social validity questionnaire suggested that they may have had misconceptions about the ACT principles and/or techniques.

Data Collection

At time point one, the average number of days the questionnaires were completed before the workshop was 33 days, with a range between one day and 140 days before the workshop. At time point two, the plan was for participants to complete the questionnaires three weeks (21 days) after the workshop. On average, the questionnaires were completed 34 days after the workshop, with a range between 21 days and 83 days post-intervention. At time point three, the plan was for participants to complete questionnaires three months (13 weeks) after the workshop. On average, the questionnaires were completed 15 weeks after the workshop, with a range between 13 weeks and 27 weeks and six days after the workshop.

Depression, Anxiety and Stress Scores at Baseline

At baseline, seven (43.75%) participants’ scores fell in the normal ranges across all three subscales of the DASS-21. The remaining nine participants’ (56.25%) scores fell in the clinical range on at least one of the DASS-21 subscales. The percentage of participants’ depression, anxiety and stress scores in the normal and clinical ranges are presented in Table 9. Seven (43.75%) of participants’ scores fell in the clinical range on the depression subscale. Five participants’ (31.25%) scores fell in the clinical range on the anxiety subscale. Eight participants’ (50%) scores fell in the clinical range on the stress subscale.

Table 9

Frequencies and Percentages of Participants' Scores in the normal and clinical ranges on the DASS-21 subscales

	Normal		Mild		Moderate		Severe		Extremely Severe	
	N	%	N	%	N	%	N	%	N	%
Depression	9	56.25	1	6.25	4	25	2	12.5	0	0
Anxiety	11	68.75	1	6.25	3	18.75	0	0	1	6.25
Stress	8	50	1	6.25	4	25	1	6.25	2	12.5

Group-Level Analyses

One-way Within-Subjects MANOVA

An initial one-way within-subjects MANOVA revealed that there was no significant effect of time on AAQ-II, CFQ, MAAS, PAC, and DASS-21 depression, anxiety and stress subscale scores, Wilks' Lambda = 0.601, F (8,7) = 0.762, p = 0.716; ηp^2= 0.225 (see Appendix X).

Quality of Life Enjoyment and Satisfaction Questionnaire

The two last items of the Q-LES-Q-SF were analysed separately and are not included in the overall score. A Friedman test revealed that there was no significant difference between medication satisfaction scores across the three time points: time point one (*M*= 3.86; *SD*= 0.378); time point two (*M*= 3.43; *SD*= 0.79); time point three (*M*= 3.43; *SD*= 0.53); [χ2 (2, N = 7) = 2.923, *p* = 0.232]. In addition, a Friedman test revealed that there was no significant difference between the overall life satisfaction and contentment scores across the three time points: time point one (*M*= 3.0; *SD*= 0.926); time point two (*M*= 3.0; *SD*= 1.0); time point three (*M*= 2.93.27; *SD*= 1.16); [χ2 (2, N = 15) = 0.545, *p* = 0.761].

Individual-Level Analyses

ACT Process Measures and Quality of Life

The magnitude of the differences in the means were small for the CFQ, MAAS, AAQ-II and Q-LES-Q-SF scores at post-intervention. At follow-up, the effect sizes were small for CFQ and Q-LES-Q-SF scores, and moderate for MAAS and AAQ-II scores (Table 10).

The mean CFQ scores at time points two and three were higher than time point one, suggesting that cognitive fusion had increased following the ACT intervention. The mean Q-LES-Q-SF scores at time points two and three were lower than time point one, suggesting that quality of life had decreased. The mean MAAS scores decreased from time point one to time point three, suggesting a reduction in mindful awareness. The mean AAQ-II scores increased from time point one to time point three, suggesting an increase in psychological inflexibility following the ACT workshop.

Table 10

Mean, Standard Deviations and Effect Sizes for ACT Process and Quality of Life Scores

		Time Point 1		Time Point 2		Time 3			
Outcome Measures	Criterion C	Mean	SD	Mean	SD	Mean	SD	Pre- to Post-Intervention Effect size	Pre-group to Follow-up Effect Size
CFQ	28.38	22.56	8.65	23.88	9.44	23.07	10.07	-0.15	-0.17
AAQ-II	23.52	20	8.92	21.06	7.77	22.80	9.59	-0.12	-0.41
MAAS	43.22	65.44	12.3	61.88	11.12	61.6	13.68	-0.29	-0.41
Q-LES-Q-SF	43.85	46.25	10.49	44.49	10.32	45.27	8.72	-0.15	-0.12

As shown in Tables 11 and 12, the majority of participants' scores on the three ACT process measures, and quality of life scores remained stable at post-intervention and follow-up. Of the scores which did not remain stable, three participant's cognitive fusion scores 'deteriorated', and three participants 'improved' and two met the RCSC criteria at post-intervention. At follow-up, two participant's cognitive fusion scores 'deteriorated' and two 'improved' and both met the RCSC criteria. Two participants' psychological flexibility scores 'deteriorated' at post-intervention and follow-up. At post-intervention, four participant's mindful awareness scores 'deteriorated'. At follow-up, three participant's mindful awareness scores 'deteriorated' and two participants 'improved'. Three participant's quality of life scores 'deteriorated' at post-intervention. At follow-up, three participant's quality of life scores 'deteriorated' and one participant 'improved'.

Table 11

RCSC Calculations for ACT Process and Quality of Life Scores from Pre- to Post-Intervention

Outcome Measures	Pre-intervention to Post-intervention (*n* = 16)			
	Number "No Change"	Number "deteriorated"	Number "improved"	Number meeting RCSC
CFQ	10 (62.5%)	3 (18.75%)	3 (18.75%)	2 (40%)
AAQ-II	14 (87.5%)	2 (12.5%)	0 (0%)	0 (0%)
MAAS	12 (75%)	4 (25%)	0 (0%)	0 (0%)
Q-LES-Q-SF	13 (81.25%)	3 (18.75%)	0 (0%)	0 (0%)

Table 12

RCSC Calculations for ACT Process and Quality of Life Scores from Pre-Intervention to Follow-up

Outcome Measures	Pre-intervention to Follow-up (*n* = 15)			
	Number "No Change"	Number "deteriorated"	Number "improved"	Number meeting RCSC
CFQ	11 (73.33%)	2 (13.33%)	2 (13.33%)	2 (50%)
AAQ-II	13 (86.67%)	2 (13.33%)	0 (0%)	0 (0%)
MAAS	10 (66.67%)	3 (20%)	2 (13.33%)	0 (0%)
Q-LES-Q-SF	11 (73.33%)	3 (20%)	1 (6.67%)	0 (0%)

Depression Anxiety Stress Scales

The means and standard deviations of the DASS-21 subscales across three time points are presented in Table 13. The size of the differences in the means were small across DASS-21 subscales at post-intervention and follow-up. The mean scores were higher at time points two and three versus time point one across all DASS-21 subscales, suggesting that participants' experiences of depression, anxiety and stress increased over time.

Table 13

DASS-21 Subscale Mean, Standard Deviations and Effect Sizes across Time

		Time Point 1 (*n* = 16)		Time Point 2 (*n* = 16)		Time 3 (*n* = 15)			
Subscales of DASS-21	External Criterion	Mean	SD	Mean	SD	Mean	SD	Pre- to Post-Intervention Effect size	Pre-group to Follow-up Effect Size
Depression	10	9.88	8.72	10.88	8.16	12.27	11.78	-0.11	-0.28
Anxiety	8	5.5	5.82	6	6.61	5.87	6.52	-0.09	-0.07
Stress	15	17	10.78	17.25	10.58	18.13	12.86	-0.02	-0.12

As shown in Tables 14 and 15, the majority of participants' depression scores remained stable at post-intervention and follow-up. Of the scores which did not remain stable, one participant's depression scores 'deteriorated' at post-intervention. At follow-up, two participant's depression scores 'deteriorated', two participants 'improved' and one participant met the RCSC criteria at follow-up. At post-intervention, two participant's anxiety scores 'deteriorated', and one participant 'improved'. At follow-up, two participant's anxiety scores 'deteriorated', two participants 'improved' and one participant met the RCSC criteria at follow-up. At post-intervention, two participant's stress scores 'deteriorated', three participants 'improved' and two participants met the RCSC criteria. At follow-up, three participant's stress scores 'deteriorated' and three participants 'improved' and all three met the RCSC criteria.

Table 14

DASS-21 Reliable Changes Indices and RCSC from Pre- to Post-Intervention

	Pre-intervention to Post-intervention (*n* = 16)			
DASS-21 Subscales	Number "No Change"	Number "deteriorated"	Number "improved"	Number meeting RCSC
Depression	15 (93.75%)	1 (6.25%)	0 (0%)	0 (0%)
Anxiety	13 (81.25%)	2 (12.5%)	1 (6.25%)	0 (0%)
Stress	11 (68.75%)	2 (12.5%)	3 (18.75%)	2 (25%)

Table 15

DASS-21 Reliable Changes Indices and RCSC from Pre-Intervention to Follow-up

	Pre-intervention to Follow-up (*n* = 15)			
DASS-21 Subscales	Number "No Change"	Number "deteriorated"	Number "improved"	Number meeting RCSC
Depression	11 (73.33%)	2 (13.33%)	2 (13.33%)	1 (16.67%)
Anxiety	11 (73.33%)	2 (13.33%)	2 (13.33%)	1 (20%)
Stress	9 (60%)	3 (20%)	3 (20%)	3 (42.86%)

Participant Factors

It is important to note that six participants reported that they felt their difficult personal circumstances had impacted their outcomes measures at time points two and/or three. These participants provided consent to report contextual information about these experiences. More specifically, two participants reported that they had started to experience health issues. One participant reported that they had started to care for another family relative who was experiencing health concerns. Another participant reported that they had experienced issues related to their employment. Lastly, two participants reported that they were experiencing significant stress related to finding new accommodation and a care provider for their relative with an ID. It is important to note that the data from these two participants had a significant impact on the mean for all outcome measures across time. More specifically, when these participants were excluded from the analyses, mean cognitive fusion, mindfulness, depression, anxiety, stress, quality of life, positive aspects of caring scores improved from baseline to follow-up. Also, when these two participants were excluded from the analyses, mean psychological inflexibility scores minimally increased across time, however the magnitude of the differences in the means had reduced. Overall, based on the six participant's reports, it is possible that these circumstances impacted the data collected.

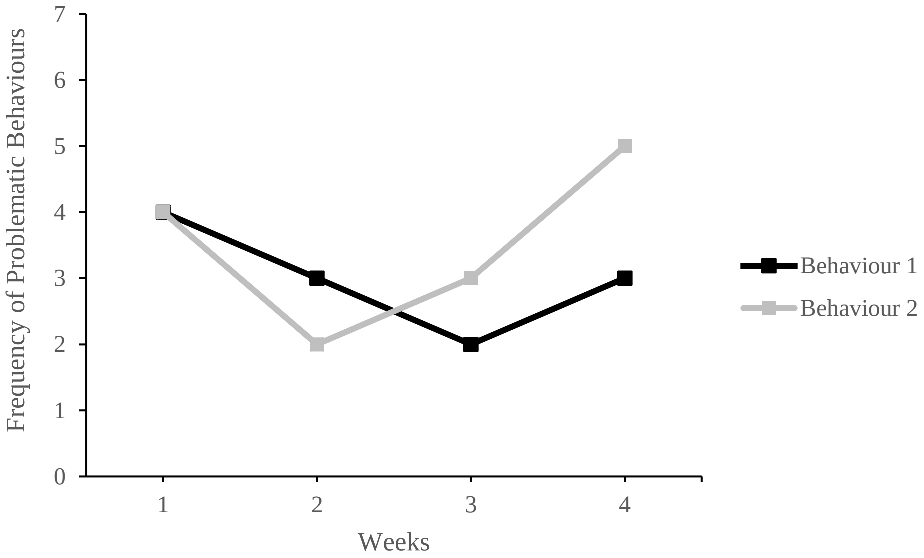
Problematic and Values-Based Behaviours

All participants were invited to identify and record the daily frequency of problematic behaviours over four weeks (one week before the workshop to three weeks post-intervention). Participants were also asked to operationalise two values-based behaviours during the workshop and complete a worksheet to record the frequencies of these behaviours over three weeks (time point two). Several participants reported that due to caring and other commitments it was difficult to complete the daily frequency of behaviours.

Three participants completed records of the daily frequency of problematic behaviours over four weeks. The specific problematic and values-based behaviours are not outlined to maintain the anonymity of the participants. Many of the problematic behaviours related to difficulties in looking after their physical and/or mental health (e.g., socialising with others). For participant A, from one-week pre-intervention to three weeks post-intervention, the weekly frequency slightly decreased for one problematic behaviour and slightly increased for another problematic behaviour (Figure 5).

Figure 5

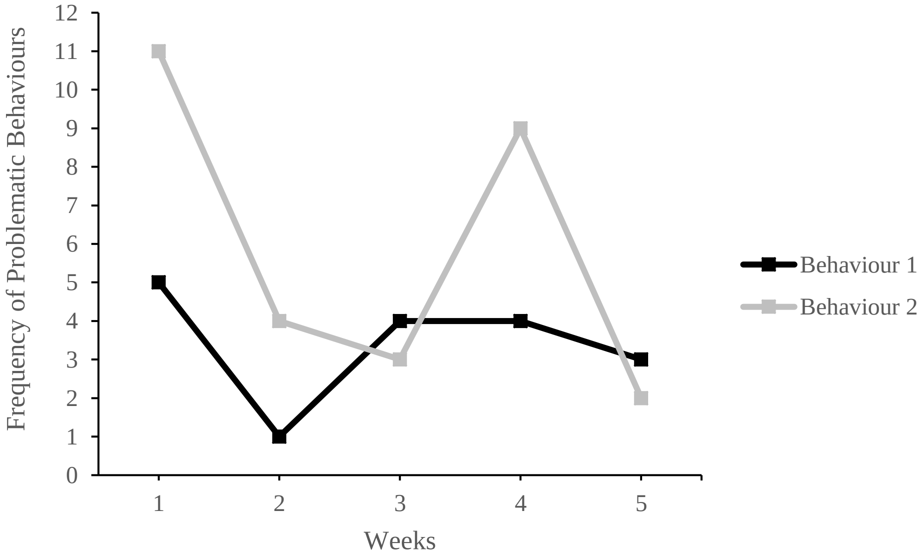
Participant A: Frequency of Two Problematic Behaviours across Time



For participant B, from one-week pre-intervention to four weeks post-intervention, the weekly frequency slightly decreased for one problematic behaviour and significantly decreased for another problematic behaviour (Figure 6).

Figure 6

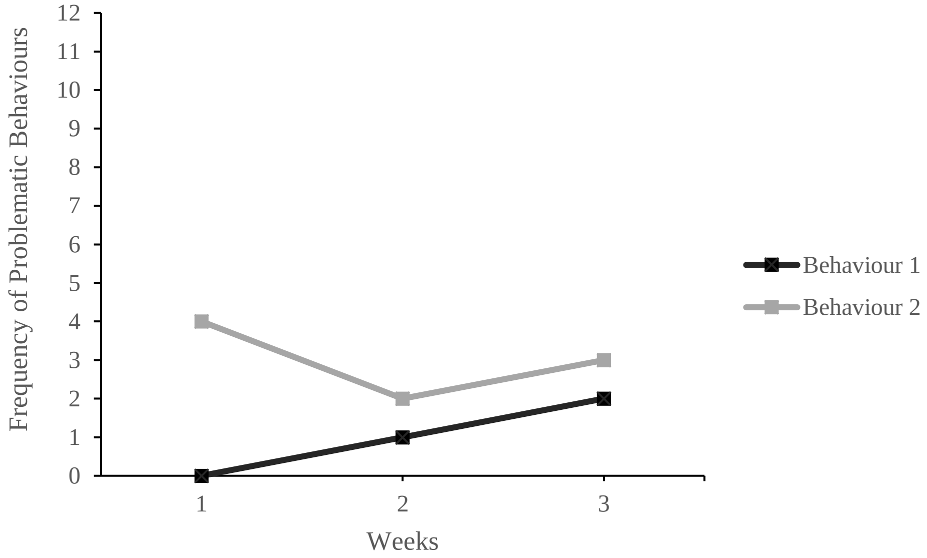
Participant B: Frequency of Two Problematic Behaviours across Time



For participant C, from one-week pre-intervention to two weeks post-intervention, the weekly frequency slightly decreased for one problematic behaviour and increased for another problematic behaviour (Figure 7).

Figure 7

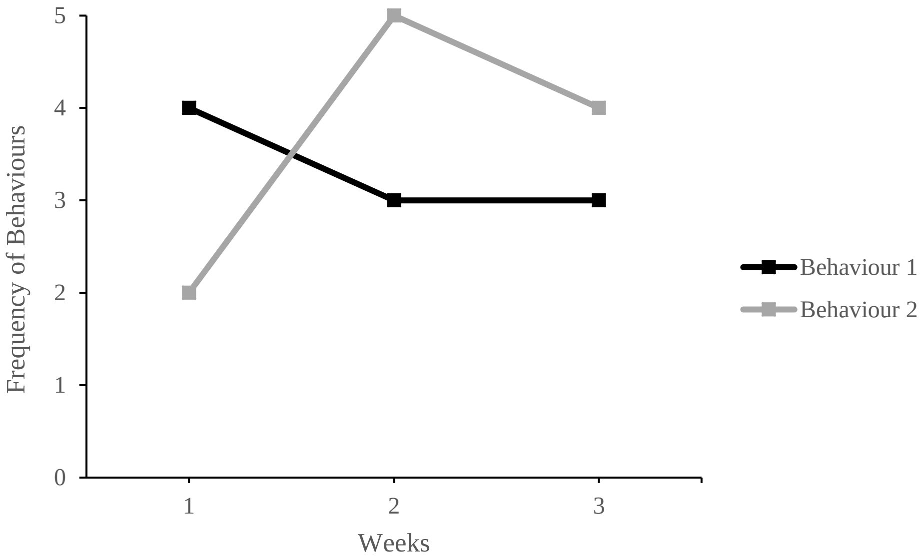
Participant C: Frequency of Two Problematic Behaviours across Time



Four participants completed records of the daily frequency of values-based behaviours three weeks post-intervention. Many of the values-based behaviour related to participants looking after their physical and/or mental health (e.g. socialising with others). For participant A, the weekly frequency increased for one values-based behaviour and decreased for another values-based behaviour (Figure 8).

Figure 8

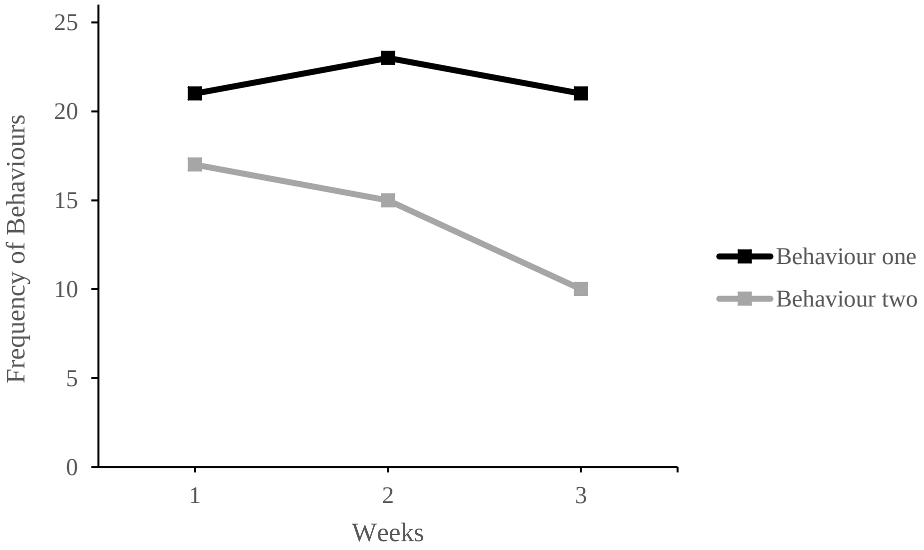
Participant A: Frequency of Two Values-Based Behaviours across Time



For participant A, the weekly frequency decreased for one values-based behaviour and remained the consistent for another values-based behaviour (Figure 9).

Figure 9

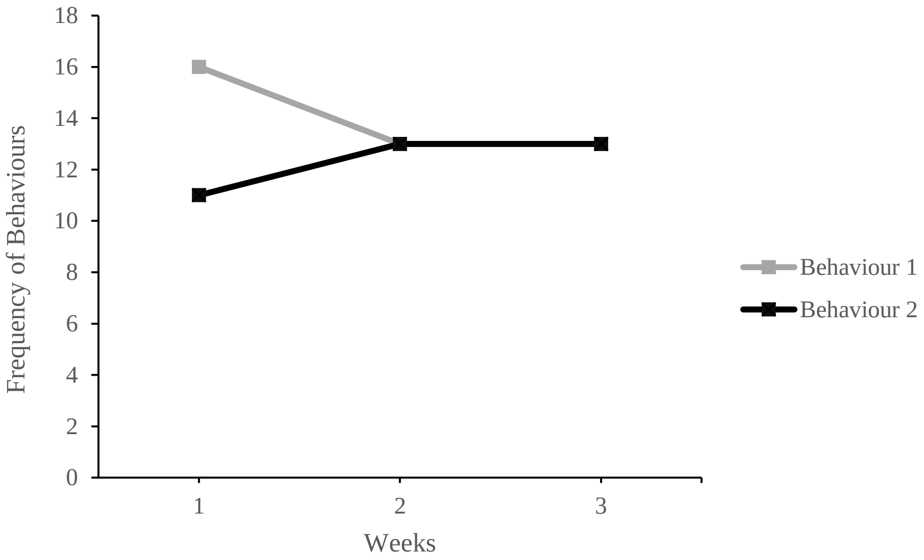
Participant A: Frequency of Two Values-Based Behaviours across Time



For participant D, the weekly frequency decreased for one values-based behaviour and increased for another values-based behaviour (Figure 10).

Figure 10

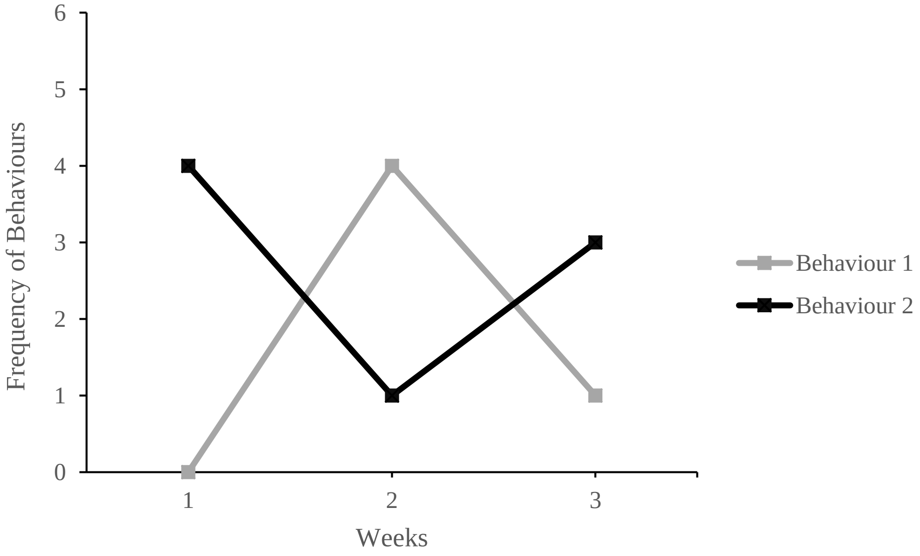
Participant D: Frequency of Two Values-Based Behaviours across Time



For participant C, the weekly frequency decreased overtime for one values-based behaviour and increased for another values-based behaviour (Figure 11).

Figure 11

Participant C: Frequency of Two Values-Based Behaviours across Time



Chapter Five: Discussion

Chapter Overview

This chapter will discuss the results from a one-day ACT workshop for family carers of adults diagnosed with IDs. The first section of this chapter will discuss the family carers' demographics and social context at baseline. The second section will summarise and discuss the group- and individual-level findings in relation to ACT outcome studies and the ACT model. The third section will discuss the treatment fidelity, social validity, and feasibility findings. The fourth section will explore the limitations and strengths of this study, as well as recommendations for future research. In the fifth section, the implications on clinical practice, policy, theory and future research will be explored. Lastly, the researcher's reflections, learning and positioning in relation to the research will be examined.

Review of Study Findings

This study evaluated the feasibility, acceptability and effects of a six-hour ACT workshop for family carers of adults with IDs. This was the first ACT intervention study within this carer population. Based on ACT research for family carers of individuals with IDs and/or ASCs, it was hypothesised that there would be significant improvements on depression, anxiety, stress, psychological flexibility, cognitive fusion, mindful awareness, quality of life and positive aspects of caregiving scores at post-intervention and follow-up compared to baseline. In line with existing research, it was also hypothesised that the ACT intervention would be feasible and socially acceptable within this carer population. Accordingly, the results will be discussed in the context of the literature outlined in the introduction chapter.

Demographics

Sixteen family carers of adults with IDs were recruited from a local LD service. The family carers reported that the majority of their adult relatives with IDs were living within their family home and had comorbid physical and/or mental health conditions, which was in line with previous research (Cooper et al., 2015; Hatton, 2017). The results revealed that the majority of family carers included in the study were mothers who were married and White-British. This finding was congruent with the majority of ACT and psychosocial carer intervention studies (Leung and Li-Tsang, 2003; Singer et al., 2007). Based on this lack of participant diversity, it has been recommended that future research should aim to recruit more diverse and under-researched family carer groups by targeting barriers to participation (Drouillard, 2019). As an example, ten family carers in this study were not able to attend the ACT workshop due to caring commitments. Hence, offering and/or helping to organise care arrangements for their relative with IDs may have enabled these carers to attend (Drouillard, 2019). For this reason, Blackledge (2004) offered free childcare for parents of children with ASCs attending an ACT intervention. Overall, this specific sample in this study limited the generalisation of these findings to other family carers groups (Kowalkowski, 2012), particularly as the experiences and needs of family carers may vary across demographics (e.g. gender) and caring relationships (e.g. siblings and grandparents) (Lee and Burke, 2018; Roberts et al., 2006).

The results revealed that nine participants' (56.25%) scores fell in the clinical range on at least one of the DASS-21 subscales. These results were consistent with previous research documenting an increased prevalence of mental health difficulties in parents of individuals with IDs (e.g., Gallagher et al., 2008; Totsika et al., 2011). Furthermore, the results revealed that the majority of family carers in this study had not been offered or received therapy in relation to carer related stress, even though they had provided support to their relatives with IDs for 26 years on average. This result was in line with existing research highlighting a paucity of formal support for this carer population (Power, 2009). Taken together, these findings emphasise the need to recognise and address the mental health needs of carers, and improve carer support provision (Arnold and McPherson, 2023).

Individual and Group-Level Analyses

A one-way within-subjects MANOVA was used to examine statistical significance on the AAQ-II, CFQ, MAAS, PAC, Q-LES-Q-SF and DASS-21 depression, anxiety and stress subscale scores at baseline, three weeks post-intervention and three months follow-up. RCSC calculations were used to examine clinical significance on AAQ-II, CFQ, MAAS, Q-LES-Q-SF, and DASS-21 depression, anxiety and stress subscale scores across three time points. The findings for each outcome measure are outlined below.

Depression

The findings revealed that depression scores increased between baseline and follow-up, and the effect size was small at post-intervention and follow-up. Also, there was no significant difference in depression scores across three time points. This finding contradicted six previous studies that had reported significant improvements in depression at post-intervention and/or follow-up (Blackledge and Hayes, 2006; Hahs, et al., 2019; Joekar et al., 2016; Jogdand and Magar, 2020; Lunsky et al., 2017; Poddar et al., 2015). However, the results were consistent with three ACT doctoral theses on parents of children diagnosed with ASCs;

these studies reported no significant improvement in depression scores from baseline to post-intervention and/or follow-up (Kowalkowski, 2012; Montgomery, 2015; O'Brien, 2011). Notably, the three studies reporting non-significant findings on depression outcomes were not peer-reviewed articles. Hence, it is possible that the unpublished studies were of lower methodological quality, which may explain the discrepancies in these findings. Equally, the three studies reporting non-significant results may not have been published due to publication bias (whereby only significant findings tend to be accepted by academic journals) (Ayorinde et al., 2020).

RCSC calculations revealed that the majority of participants' depression scores remained stable at post-intervention and follow-up, which was consistent with previous research (O'Brien, 2011). One participant's depression scores 'deteriorated' at post-intervention. At follow-up, two participant's depression scores 'deteriorated', two participants 'improved' and one participant met the RCSC criteria at follow-up. Participants who experienced a deterioration in their depression scores also reported significant life stressors which they felt had impacted their scores, and therefore could explain this finding. As two participants 'improved' at follow-up but not at post-intervention, it is plausible that these participants needed additional time to benefit from the ACT intervention, in line with an incubation effect (Blackledge and Hayes, 2006).

Overall, these findings indicate that the ACT workshop did not have a significant impact on depression scores. Nonetheless, the results indicated that the majority of family carers included in this study were not in the clinical range on depression, anxiety and stress subscales at baseline. This may have minimised the magnitude of potential treatment gains and thereby reduced statistical power (Drouillard, 2019; Garzon, 2012). Also, there is some evidence that ACT interventions have larger effects for individuals with higher levels of distress (Levin et al., 2017), anxiety, stress and depression symptoms (O'Brien, 2011). Moving forward, future research should aim to recruit family carers with higher mental health needs and/or at points when family carers may be experiencing higher levels of distress, for example after their relative has received an initial diagnosis (Drouillard, 2019). This could be achieved by screening family carers for clinically significant levels of mental health symptoms or distress (O'Brien, 2011).

Anxiety

The results revealed that the mean anxiety scores were higher at post-intervention and follow-up versus baseline, and the effect size was small at post-intervention and follow-up. However, there was no significant difference in anxiety scores across the three time points. This finding was incongruent with two research studies demonstrating significant improvements in anxiety symptoms at post-intervention (Jogdand and Magar, 2020; Poddar et al., 2015). Conversely, the results were consistent with findings from two ACT studies with mothers of children diagnosed with ASCs. For example, Joekar et al. (2016) reported no significant differences in anxiety between ACT and control groups at post-intervention. Kowalkowski (2012) reported no significant improvement on anxiety scores from baseline to follow-up, but reported that there was trend towards a reduction in anxiety scores.

RCSC analyses revealed that the majority of participants' anxiety scores remained stable at post-intervention and follow-up, which was consistent with previous research (O'Brien, 2011). At post-intervention, two participant's anxiety scores 'deteriorated', and one participant 'improved'. At follow-up, two participant's anxiety scores 'deteriorated', two participants 'improved' and one participant met the RCSC criteria at follow-up. Three of the four participants whose anxiety scores deteriorated also reported significant life stressors which they felt had impacted their scores**,** and thus could explain these findings.

In summary, these results indicated that the ACT workshop did not have a significant effect on anxiety scores, although there are a number of possible explanations for this finding. Interestingly, the non-significant results at a group-level were reported in unpublished studies and hence could be attributed to lower methodological rigour (e.g., Ayorinde et al., 2020). Secondly, as mentioned above, most of the family carers were in the non-clinical range on the anxiety subscale, which may have minimised the extent of treatment gains (Drouillard, 2019). Thirdly, it is possible that using the DASS-21 may not be the best measure to evaluate the effectiveness of ACT as the ACT model does not aim to reduce symptoms, unwanted thoughts and feelings, or suffering (Blackledge, 2004; Luoma et al., 2007; O'Brien, 2011). Equally, it is plausible that the family carers in this study became more aware of unwanted inner experiences (e.g. anxiety symptoms) and negative self-evaluations following the ACT intervention (Bacon et al., 2014; O'Brien, 2011). In fact, some ACT researchers have posited that increased symptom reporting after ACT interventions can be attributed to improved acceptance of symptoms (Bach and Hayes, 2002). Fourthly, the results may have been confounded by participant factors, particularly due to the small sample size. Lastly, these participants may not have been able to understand or implement the ACT skills due to higher levels of psychological distress (Zody, 2017).

Stress

The results demonstrated that the mean stress scores slightly increased between baseline and follow-up, and the effect size was small at post-intervention and follow-up. Moreover, statistical analysis revealed there was no significant difference in stress scores across three time points. This finding was consistent with research demonstrating no significant differences in stress scores from pre- to post-intervention (Montgomery, 2015; O’Brien, 2011). Similarly, other research has reported no significant differences between ACT and control groups on stress scores at post-intervention (Corti et al., 2018; Joekar et al., 2016; Marino et al., 2021). However, these results contradicted three ACT studies reporting a significant improvement in stress scores from pre- to post-intervention (Jogdand and Magar, 2020; Lobato et al., 2022; Lunsky et al., 2017). In summary, inconsistent findings on the effectiveness of ACT for stress in family carers of individuals with IDs and/or ASCs have been documented. Future research is required to explain why some family carers report improvements in stress following ACT interventions and others do not.

RCSC analyses revealed that the majority of participants’ stress scores remained stable at post-intervention and follow-up, which was consistent with previous research (O’Brien, 2011). At post-intervention, two participant’s stress scores ‘deteriorated’, three participants ‘improved’ and two participants met the RCSC criteria. At follow-up, three participant’s stress scores ‘deteriorated’ and three participants ‘improved’ and all three met the RCSC criteria. Three of the four participants whose cognitive fusion scores deteriorated also reported significant life stressors which they felt had impacted their scores (e.g. health issues), and thus could explain these findings.

Taken together, these findings indicate that the ACT workshop did not have a significant impact on stress scores. As described above, the family carers may have become more aware of stress symptoms following the ACT intervention (Bacon et al., 2014; O’Brien, 2011). Another possible reason for the non-significant difference and slight increase in stress scores was that the ACT intervention workshop did not specifically target and/or ameliorate the stressors experienced by these family carers (Montgomery, 2015). Potential stressors within this carer population include caregiver stigma (Ali et al., 2012; Mitter et al., 2019; Song et al., 2018), financial and employment disadvantages (Ouyang et al., 2014; Saunders et al., 2015), and poorer physical health outcomes (Gallagher and Whiteley, 2013; Song et al., 2018). Additionally, based on criticisms of carer interventions, it is possible that the ACT workshop did not fully account for and/or address the socio-political influences on caregiving, including significant cuts to public services and benefits (Knight, 2013). As such, it has been argued that carer interventions should be targeted at social-political level, such as the development of public policy (McConnell and Savage, 2015).

Positive Aspects of Caregiving

The findings revealed that PAC scores slightly decreased from baseline to follow-up, however there was no significant difference in PAC scores across three time points. This finding was consistent with one study which reported no significant improvements in positive aspects of caregiving from baseline to follow-up (Kowalkowski, 2012). Nevertheless, Kowalkowski (2012) reported a significant difference in PAC scores from post-intervention to follow-up. Kowalkowski (2012) attributed this finding to improvements in mindfulness in line with research demonstrating that mindfulness can increase experiences of positive emotions (Fredrickson et al., 2008). As such, it could be argued that the non-significant difference in PAC scores could be explained by the non-significant changes in mindful awareness. Future research should investigate the relationship between mindfulness and PAC scores within this carer population (Kowalkowski, 2012). Alternatively, it is possible that after attending the ACT workshop, participants were more able to accept (rather than avoid) unwanted inner experiences, including those related to negative aspects of caregiving (e.g., O'Brien, 2011; Corti et al., 2018). For example, Bach and Hayes (2002) reported higher levels of positive psychotic symptoms following an ACT intervention, but significantly lower levels of re-hospitalisation. The authors posited that the increased levels of symptoms could be attributed to the improved acceptance of symptoms (Bach and Hayes, 2002).

In addition, this was the first study to report PAC scores for family carers of adults with IDs. The average PAC score at baseline was 29.38, which was lower than the PAC levels reported by mothers of children with ASCs (M = 31.62) (Kowalkowski, 2012) and dementia caregivers (M =34.0) (Tarlow et al., 2004). Notably, levels of PAC have been reported to moderate treatment outcomes for dementia caregivers (Hilgeman et al., 2007). Therefore, this could be investigated in future ACT studies involving family carers of adults with IDs (e.g., Kowalkowski, 2012).

Quality of Life Enjoyment and Satisfaction

The findings revealed that the quality of life scores were lower at post-intervention and follow-up than baseline, suggesting that quality of life had decreased overtime. The effect size for quality of life scores was small at post-intervention and follow-up. There was no significant difference in Q-LES-Q-SF scores across three time points, which was consistent with other research (Joekar et al., 2016). However, these findings contradict ACT research reporting significant improvements in psychological quality of life in parents of children and adolescents with ASCs (Montgomery, 2015; Poddar et al., 2015). Although, the discrepancy in these findings could be explained by the different family carer populations and quality of life outcome measures used across the studies. More specifically, it is possible that the quality of life of family carers in this study may have deteriorated after many years of caregiving (Fernández-Ávalos et al., 2020). In addition, Poddar et al. (2015) reported significant improvements in psychological quality of life, but no significant improvements in physical, social and environmental quality of life. Consequently, it is possible that this study did not detect changes across different quality of life domains.

RCSC analyses revealed that the majority of participants' quality of life scores remained stable at post-intervention (81.25%) and follow-up (73.33%). Three participant's quality of life scores 'deteriorated' at post-intervention and follow-up. One participant's quality of life scores 'improved' at follow-up. The three participants whose quality of life scores deteriorated could be explained by significant life stressors (e.g., starting to care for another relative), rather than the ACT intervention.

Overall, the findings indicated that the ACT workshop did not have a significant impact on quality of life scores. It is possible that using a quality of life measure specifically for family carers, such as the Adult Carer Quality of Life Questionnaire (Joseph et al., 2012), may have produced different results. Additionally, it is possible that the lack of improvement in quality of life outcomes could be explained by non-significant changes on ACT processes. For example, improvements in parental quality of life have been positively associated with MAAS scores (Rayan and Ahmad, 2018), and negatively associated with AAQ-II scores (O'Brien, 2011). Lastly, it is possible that the ACT intervention did not target or address external factors negatively associated with quality of life, such as a financial disadvantages and caregiver stigma (e.g., Mitter et al., 2019; Yoong and Koritsas, 2012).

Psychological Flexibility

The results indicated that AAQ-II scores increased from baseline to follow-up, suggesting an increase in psychological inflexibility following the ACT workshop. The effect size for AAQ-II scores were small at post-intervention and moderate at follow-up. However, there was no significant difference in AAQ-II scores across three time points. Based on ACT intervention studies for parents of children with IDs and/or ASCs, these non-significant findings were consistent with one study (Kowalkowski, 2012), but were in contradiction with four previous studies reporting significant improvements in psychological flexibility (Fung et al., 2018; Lobato et al., 2022; Marino et al., 2021; Poddar et al., 2015).

RCSC analyses revealed that the majority of participants' psychological flexibility scores remained stable at post-intervention and follow-up. This finding was not consistent with research by Lobato et al. (2022) reporting that the majority of family carers of children with IDs psychological flexibility scores 'improved' or 'recovered' at post-intervention and follow-up. In this study, two participants' psychological flexibility scores 'deteriorated' at post-intervention and follow-up; both of whom were experiencing significant life stressors which they felt had impacted their scores.

The findings indicated that the ACT workshop did not have a significant impact on psychological flexibility. It has been posited that a one-day ACT workshop may not be adequate to teach acceptance skills to family carers, particularly when they are feeling distressed (Zody, 2017). Similarly, other researchers have reported that clients can often struggle to foster acceptance skills after receiving long-standing societal messages to attempt to control their inner experiences (Luoma et al., 2007; Smith, 2017). As an example, Blackledge and Hayes (2006) reported no significant differences in AAQ scores from pre- to post-intervention, but reported significant improvements from post-intervention to follow-up. Based on this incubation effect, it has been recommended that family carers may need additional time and support to develop their acceptance skills (Bacon et al., 2014; Blackledge and Hayes, 2006). Lastly, the family carers recruited in this study may have had higher levels acceptance towards their relative diagnosed with IDs than other carers in this population (e.g., Drouillard, 2019). They may have also been more willing to explore their difficulties and change their behaviour (Zody, 2017); both of which may have minimised the extent of treatment effects on the AAQ-II (Drouillard, 2019).

Additionally, some researchers have criticised the AAQ-II for not equally measuring the breadth and depth of all six core ACT processes, and have argued that the AAQ-II predominantly focuses on acceptance and defusion processes (Francis, 2016). Future ACT studies may consider using more psychometrically robust measures of psychological flexibility (Axenova, 2022), such as the Comprehensive Assessment of Acceptance and Commitment Therapy Processes (Francis, 2016). In addition, the small sample size reduced the statistical power of the tests and the probability of gaining a statistically significant result (Kowalkowski, 2012).

Additionally, Murrell et al. (2009) hypothesised that parents may interpret the items of AAQ-II differently at post-intervention as their understanding of acceptance and experiential avoidance has developed, which may act as a confounding variable. Lastly, the AAQ-II is a general measure of psychological flexibility, and hence may not have assessed whether the participants learned to accept unwanted inner experiences linked to caring for a relative with IDs (Blackledge, 2004). For example, an ACT intervention for diabetes management resulted in significant improvements on acceptance, cognitive defusion and valued behaviour linked to diabetes; however there was no significant changes on the AAQ (Gregg, 2004). Prospective research should investigate the effects of ACT on ACT processes specifically linked to caregiving.

Cognitive Fusion

The findings revealed that cognitive fusion scores were slightly higher at post-intervention and follow-up compared to baseline. The effect size was small for cognitive fusion at post-intervention and follow-up. However, there was no significant difference in cognitive fusion scores across time. This finding was consistent with the results from one study (Corti et al., 2018), but contradicted four studies reporting improvements in cognitive fusion at post-intervention (Blackledge and Hayes, 2006; Corti et al., 2018; Fung et al., 2018).

RCSC calculations revealed that the majority of participants' cognitive fusion scores remained stable at post-intervention and follow-up. Of the scores which did not remain stable, three participant's cognitive fusion scores 'deteriorated', and three participants 'improved' and two met the RCSC criteria at post-intervention. At follow-up, two participant's cognitive fusion scores 'deteriorated' and two 'improved' and both met the RCSC criteria. The three participants whose cognitive fusion scores deteriorated also reported significant life stressors which they felt had impacted their scores (e.g. health issues) and could explain these findings.

Overall, the findings indicated that the ACT workshop did not have a significant impact on cognitive fusion scores. However, there are several potential explanations for the non-significant findings on cognitive defusion outcomes. Firstly, some participants may have misunderstood or misapplied the cognitive defusion techniques (Smith, 2017). For example, previous studies have reported that some clients have used defusion to dispute their thoughts (Bloy, 2013), and/or as an experiential avoidance technique (Smith, 2017). As such, it is possible that the non-significant differences in cognitive fusion scores across time could be explained by issues related to participants' understanding and implementation of the cognitive defusion; however this was not examined in this study. Secondly, it is possible that participants became more aware of moments of cognitive fusion post-intervention (Corti et al., 2018). Thirdly, the CFQ may not have assessed whether the participants learned to defuse from unwanted thoughts related to caring for a relative diagnosed with IDs (Blackledge, 2004). Fourthly, Bolderston et al. (2019) reported that the state cognitive fusion questionnaire was significantly more sensitive than the original CFQ after brief defusion exercises. Therefore, the CFQ may not have been sensitive enough to detect differences in cognitive fusion post-intervention. Future ACT studies should consider using the state CFQ (Bolderston et al., 2019).

Mindful Awareness

The results revealed that there was a decreasing trend in mindful awareness across time. The effect size was small for mindful awareness at post-intervention and moderate at follow-up, suggesting that the magnitude of change had increased over time. However, there was no significant difference in mindful awareness scores across three time points, which was consistent with previous findings from three studies (Hahs, et al., 2019; Kowalkowski, 2012; O'Brien, 2011) and contradicted one study reporting improvements in mindfulness at post-intervention (Corti et al., 2018).

RCSC analyses revealed that the majority of participants' mindful awareness scores remained stable at post-intervention and follow-up, which was consistent with previous research (O'Brien, 2011). At post-intervention, four participant's mindful awareness scores 'deteriorated'. At follow-up, three participant's mindful awareness scores 'deteriorated' and two participants 'improved'. Three of the five participants whose mindfulness scores deteriorated also reported significant life stressors which they felt had impacted their scores (e.g. health issues) and therefore could explain these findings.

Taken together, the results indicated that the ACT workshop did not have a significant impact on mindfulness scores. There are number of possible explanations for the non-significant differences and decreasing trend in mindfulness scores. Firstly, family carers may have learned to observe their private events (e.g. thoughts) before learning to accept and allow inner experiences without judgement (O'Brien, 2011). Secondly, it is therefore possible that the family carers may have become more aware of lower levels of mindfulness-based behaviours and moments of disconnection (Corti et al., 2018). This process has been hypothesised to precede improvements in mindful awareness scores (Corti et al., 2018). Accordingly, it has hypothesised that individuals may need a longer time to develop mindfulness skills (Corti et al., 2018). Thirdly, other studies have reported that participants have found it difficult to comprehend and implement mindfulness (e.g., Bacon et al., 2014). For example, participants have been reported to use mindfulness as an experiential avoidance technique, for example to relax, distract or reduce unwanted experiences (Bacon et al., 2014). As such, it is possible that issues related to participants' understanding and implementation of the mindfulness could have contributed to these findings; however this was not monitored or assessed in this study. Fourthly, as described above, inconsistent results on the effectiveness of ACT on mindfulness for parents of individuals with IDs and/or ASCs have been documented (O'Brien, 2011). Lastly, it is possible that the family carers in this study did not receive adequate mindfulness skills training (O'Brien, 2011). Future research is required to investigate the effectiveness of ACT on mindful awareness in this carer population.

Values-Based and Problematic Behaviours

Only five participants recorded the frequency of their problematic and/or values-based behaviours. Several participants reported that due to caring and other commitments it was difficult to record the daily frequency of these behaviours. Of the family carers who completed the behavioural records, some carers reported that they had forgotten to complete the behavioural records and recorded the behaviours retrospectively, which may have been increased inaccuracies (O'Brien, 2011). Overall, it was difficult to draw any accurate conclusions about the effects of ACT on overt behaviours due to the absence of stable baseline data (O'Brien, 2011) and the limited data available. Future research should aim to minimise the barriers to family carers recording behaviours (e.g., using online technology) or more regularly remind family carers to complete their behavioural records (O’Brien, 2011).

Additionally, it is important to note that the frequency of values-based and problematic behaviours were based on participants’ self-reports, which may have been less reliable and accurate than direct observations of overt behaviours (e.g., Blackledge, 2004; O’Brien, 2011). Moreover, changes in the frequency of these behaviours may have been influenced by the process of self-monitoring and recording (Burke et al., 2011; Newcomb and Mustanski, 2014), rather than the ACT intervention. For these reasons, future studies should use direct observations of participant’s problematic and values-based behaviours to minimise the effects of self-monitoring, and to improve the accuracy of the data (Blackledge, 2004).

Problematic Behaviours

Based on the data from three participants, the results indicated that there were mixed findings on the daily frequency of problematic behaviours. One participant reported a reduction in two problematic behaviours over time, and two participants reported that one problematic behaviour had increased and another problematic behaviour had reduced. Previous studies have documented a decrease in problematic behaviours. For example, Lobato et al. (2022) reported a decrease in punitive and hostile familial interactions. Similarly, Twohig et al. (2007) reported that participants no longer used marijuana following an ACT intervention. It is possible that the discrepancy in these findings could be explained by differences in the intervention format and duration. For example, Twohig et al. (2007) used eight 90 minute individual sessions, and Lobato et al. (2022) used three sessions lasting three hours each.

Based on the mixed findings found both within and across participants, it is possible that the ACT intervention was more effective at reducing the frequency of certain problematic behaviours more than others. Future research should examine the impact of ACT on a variety of problematic behaviours within this carer population, such as negative interactions with their relative diagnosed with IDs and other problematic caregiving behaviours (e.g. O’Brien, 2011). Similarly, it is possible that the ACT intervention needed to be more tailored to address the problematic behaviours identified by participants. For example, in the workshop, carers could have been asked to think about practical and cognitive barriers (e.g. fusion) to reducing their problematic behaviours. In summary, future research should examine the effectiveness of ACT on problematic behaviours within this carer population (e.g., Lobato et al., 2022).

Values-Based Behaviour

Based on the data from three participants, there were mixed results on the daily frequency of values-based behaviour. Interestingly, there have been mixed findings on the efficacy of ACT on values-based behaviour for parents of children with ASCs within the research literature. O'Brien (2011) reported that the majority of valued-living and valuing behaviour questionnaire scores remained stable at individual levels. Additionally, Han et al. (2021) completed a systematic review on ACT for family caregivers of individuals with chronic conditions (including neurodevelopmental disorders). The authors reported that there were no significant improvements of ACT on valued living based on six studies. Conversely, two research studies on parents of individuals with ASCs have reported improvements in personal values in everyday life (Marino et al., 2021) and valued-living scores (Fung et al., 2018). Similarly, Gould et al. (2018) documented improvements in the frequency of parent's overt valued-behaviours. Nonetheless, the discrepancies in these findings could be explained by differences in the intervention format and duration.

Furthermore, there are a number of other potential explanations for the lack of improvement in values-based behaviour across and within family carers. For example, it is possible that family carers of adults with IDs may have a longer history of caring behaviours, and thus may be more resistant to changing their behaviours (e.g., Gould et al., 2018). Furthermore, there is some evidence that family carers may underreport their occurrences of values-consistent behaviours (Gould et al., 2018). Additionally, many of the values-based behaviours selected by the family carers were related to their own health and wellbeing life domain. However, due to conflicting demands, it may have been difficult to invest their time and energy in this value domain (Fernández-Ávalos et al., 2020; Fung et al., 2018). It is therefore possible that the carers were acting in line with their values (e.g. kindness), but were focusing their time and energy on using their values in a different life domain, such as parenting or family relationships (e.g., Harris, 2009). In summary, it could be that the behavioural data did not capture all the effects of the ACT intervention on values and values-congruent behaviour (Gould et al., 2018). As noted by O'Brien (2011), future research should examine the impact of ACT on values-guided behaviours across different valued-life domains, including domains related to caregiving (e.g. parenting).

Social Validity

Ten participants completed the social validity questionnaire. Based on the quantitative feedback, all family carers reported that they had benefited at least ‘somewhat’ from the workshop across all five Likert-scale items. These findings were consistent with previous ACT studies reporting positive quantitative feedback from parents of children with ASCs (e.g., Corti et al., 2018; Lunsky et al., 2017). Although the quantitative feedback was generally positive, it is important to note that six participants did not complete the questionnaire and therefore these findings may not reflect the experience of all the participants. Similarly, qualitative feedback on the workshops was predominantly positive, in accordance with previous studies (Drouillard, 2019; Kowalkowski, 2012). Four family carers commented that they valued developing relationships, sharing their experiences and learning from others in similar circumstances, which was consistent with previous research (Blackledge, 2004; Drouillard, 2019; Lunsky et al., 2017; O’Brien, 2011). Based on these beneficial group therapy processes (see Ezhumalai et al., 2018), future psychosocial interventions should consider using group formats (such as workshops) within this carer population.

Four participants spoke about most liking the videos presented in the workshop, and therefore future ACT interventions should consider including these. The family carers in this study recommended some changes to the ACT workshop, some of which have been documented in the research literature (Drouillard, 2019). Recommendations included additional and/or follow-up sessions, and larger group sizes which should be considered in future ACT studies.

Nevertheless, it is possible that participants’ responses on the social validity questionnaire may have been influenced by social desirability bias (Chang et al., 2019). Also, some family carers reported that they did not find some of the ACT concepts helpful and/or did not feel their behaviour or coping strategies had changed following the ACT intervention; similar findings have been reported in other ACT studies (Bacon et al., 2014; Drouillard, 2019). Overall, the social validity data indicated that the family carers were satisfied with the ACT workshop and found the intervention to be highly acceptable. Future research is required to explain differences in social validity reports across different family carers of individuals with IDs and/or ASCs.

Feasibility

The results revealed that the ACT workshop for family carers would not be deemed feasible as two of the four feasibility criteria were not met (see Fowler et al., 2021). With regards to the two unmet feasibility criteria, at least 70% of enrolled participants did not complete the whole workshop or the outcome measures from baseline to three months follow-up. Both findings illustrate the significant challenges of this research with regard to data collection and participant retention, which has been documented in similar studies (Garzon, 2012; O'Brien, 2011; Zody, 2017).

In this study, due to participants' care and personal commitments, it was difficult for some carers to attend screening appointments or complete the outcome measures, intervention or study. For example, virtual or telephone meetings with some family carers had to be cancelled and/or rescheduled on multiple occasions. The researcher tried to minimise these barriers by being flexible with appointment times (e.g. offering evening time slots) and sending postage-paid envelopes. Nonetheless, some family carers were not able to be contacted despite sustained efforts. Future research should aim to involve other professionals (e.g. LD nurses) in the data collection procedures where possible (O'Brien, 2011). For example, this could involve asking other professionals to support with arranging screening appointments or collecting outcome measures.

Overall, it is possible that the ACT workshop may not be a feasible intervention for this carer population. Equally, it is possible that the feasibility criteria used was too stringent for this carer population. The feasibility criteria was originally used for caregivers of adults with dementia who accessed the intervention over the telephone, and may have had different needs and experiences (Fowler et al., 2021). For example, Garzon (2012) reported that none of the parents of children with autism in their study completed the outcome measures at follow-up. In future, the study design or intervention could be changed to the increase feasibility of future ACT interventions and research. This could involve reducing the number of outcome measures completed by family carers, offering participant compensation to increase participant recruitment or retention (Garzon, 2012), or adapting the intervention (e.g. offering multiple shorter sessions, telephone sessions or individual sessions).

Treatment Fidelity

The group facilitators completed self-reports of the ACT-FM (O'Neill et al., 2019) to monitor and measure treatment fidelity for each workshop. Analysis revealed that there was a high degree of adherence and the intervention was delivered as intended. Based on the ACT-FM, the average total consistent ACT score was 29.30 and the average total inconsistent ACT score was 1.3 across the three ACT workshops, which was comparable to scores reported in previous studies (Casey et al., 2022; Robinson et al., 2023; Rose et al., 2023; Stynes and McHugh, 2023). Moreover, the facilitators ticked off the exercises completed from the ACT intervention protocol, and no exercises were omitted or added. Taken together, this data indicated that there was a high degree of adherence and the intervention was delivered as intended. This suggests that the outcomes reported in this study can be linked to the ACT intervention, rather than treatment fidelity issues (Plumb and Vilardaga, 2010; Sanetti et al., 2021).

Alternatively, this self-reported treatment fidelity data may have been less reliable, accurate, comprehensive and less predictive of intervention outcomes, compared with direct observations of treatment fidelity reported by an independent rater (Gresham et al., 2017; Sanetti and Collier-Meek, 2014). Future research should use direct measures of treatment fidelity (via direct observation, audio or videotapes) which are completed by raters independent to the study, with at least four data points per observation (Gresham et al., 2017; Hildebrand et al., 2012).

Strengths

This study had several strengths. It was the first to examine the effectiveness, feasibility and acceptability of ACT for family carers of adults with IDs. Additionally, a range of intervention adaptations were offered and/or implemented to allow family carers to attend the workshop and be responsive to their relatives with IDs. Although the impact of these adaptations was not assessed, it is possible that participant enrolment, engagement and retention was improved due these modifications. Moreover, in comparison with the criticisms of other carer interventions (see Chard, 2022; Deacon et al., 2020), the ACT workshop aimed to improve the participants’ own wellbeing, rather than placing responsibility on family carers to support and/or focus on the wellbeing of their relatives with IDs.

Outcome Measures

There were a number of strengths related to the outcome measures used in this study. Firstly, this study used a range of standardised, validated and reliable outcome measures to assess the effects of the ACT intervention. These outcomes measured family carers’ mental health, quality of life, ACT processes and positive aspects of caring. The outcomes were collected over three points which allowed for an analysis of treatment effects at post-intervention and follow-up. The inclusion of the participant-reported frequency of problematic and values-based behaviours provided further data in relation to the impact of the ACT workshop on their daily lives. Overall, the range and frequency of outcome measurement increased the likelihood of detecting all the intervention effects. Future ACT studies could use these outcome measures to directly compare their findings to this study.

Statistical Analysis

Another strength of the study was that a sample size calculation was completed and allowed for a 15% drop out rate. As such, this increased the statistical power and probability of the results reaching statistical significance (Kang, 2021). Furthermore, this study used a MANOVA (instead of individual tests) and post-hoc comparisons were not completed following a non-significant omnibus test. As a consequence, this method of analysis increased the statistical power (Futschik et al., 2019), and reduced the risk of a type one error (Tian et al., 2018). Moreover, based on RCSC calculations it was possible to examine reliable change and clinical significance. Although established norms were not available for this carer population, an extensive review of the norms available in the literature was completed by the author, and the norms were selected based on the sample most similar to the participants included this study (e.g. based on gender and age).

Carer Involvement

In line with recommendations from previous parent involvement research (e.g., Beighton et al., 2019), this study used feedback from a group of family carers to inform the study design and methods. More specifically, carer feedback was used to inform the duration, format and structure of the ACT intervention, the recruitment leaflets, and the inclusion and exclusion criteria. Previous studies have revealed that stakeholder engagement in outcomes research has improved participant recruitment, study quality, social validity, and the relevance and feasibility of studies (Forsythe et al., 2019; Maurer et al., 2022). Although the effects of stakeholder involvement was not evaluated in this study, it is plausible that the input from family carers may have resulted in valuable impacts. Future ACT intervention studies within this population should aim to maximise opportunities for stakeholder involvement and engagement throughout the research process.

Intervention

There were a number of strengths related to the intervention. Firstly, the intervention covered all six core ACT processes, in contrast with previous studies (e.g., Poddar et al., 2015; Salimi et al., 2019). Secondly, based on the feedback from carers and previous research recommendations (see Blackledge, 2004), family carers had the opportunity to socialise for 30 minutes before and after the workshop. The qualitative feedback revealed that many family carers reported that they had benefited from socialising and hearing about the caregiving experiences from other group members. Thirdly, the participant workshop handouts included links to the videos used in the workshop, and therefore participants had access to the videos to recap and practise their ACT skills (e.g. leaves on a stream exercise). Lastly, the intervention was delivered in a one-day ACT workshop, as opposed to individual or multiple sessions of ACT, which may have increased the likelihood of family carers being able to attend the workshop, given their caring commitments (Blackledge, 2004).

Treatment Fidelity and Social Validity

Another strength of this study was the inclusion of treatment fidelity measures which allowed for the treatment outcomes to be linked to the ACT intervention, rather than treatment fidelity issues (Plumb and Vilardaga, 2010). Additionally, the inclusion of social validity measures allowed for an evaluation of social acceptability and satisfaction of ACT for family carers of adults with IDs. This was particularly important as it was the first ACT outcome study within this population. Nevertheless, additional research is required to evaluate the social validity of ACT within this population and the associated impacts on intervention outcomes (e.g., Garcia et al., 2021).

Limitations and Recommendations

A number of limitations should be taken into consideration when interpreting the results of this study. Firstly, the author had not attended training on ACT which may have negatively impacted the design and implementation of this study (e.g., Busch, 2009). Nonetheless, the study was based on the review of other studies and contained all the necessary components. Secondly, this study did not utilise a control group and random allocation, and therefore did not sufficiently control for non-specific treatment factors. Examples of non-specific treatment factors included social desirability bias, therapeutic alliance, group processes (e.g., meeting other carers), and participant expectancy, effort and attention (Blackledge, 2004; Chang et al., 2019; Guidi et al., 2018; Juvin et al., 2021). Consequently, this study may have overestimated the efficacy of the ACT intervention due to these confounding variables (Guidi et al., 2018).

Ideally, a RCT would have been used in this study, however this was beyond the scope of a doctoral thesis. Future research should use RCTs with active control groups to accurately evaluate the effects of ACT within this population (Garcia et al., 2021; Guidi et al., 2018).

Sample

A major limitation of this study was the small sample size and non-probability sampling method used, which may have decreased the external validity of the findings and increased the risk of sampling bias (Drouillard, 2019; Patel et al., 2003). In addition, the small sample size reduced the statistical power of the inferential tests and undermined the probability of gaining statistical significance (Kang, 2021). Equally, the sample size calculation was based on a large effect size (f = 0.4). However, the effect sizes found in this study were small or moderate across all outcome measures. It was not possible to recruit a larger sample size within the time frame of a doctoral thesis; however, it is likely that a larger sample size was required in this study to detect smaller differences in treatment outcomes (Serdar et al., 2021). Future ACT studies should aim to recruit family carers of adults with IDs based on a sample size calculation and should consider using the effect sizes reported in this study to inform their sample size estimations (Serdar et al., 2021).

Outcome Measures

Another limitation of the study was the lack of long-term follow-up data due to the constraints of the thesis timeframe. The ACT effects may have significantly changed (i.e., improved or deteriorated) over longer follow-up periods (Lobato et al., 2022). Consequently, it was not possible to evaluate the long-term impact and maintenance of the ACT intervention in this study. Future research on ACT in this population should aim to collect follow-up data over longer time periods (e.g. 12-months).

Another limitation related to the variation in the timing of data collection across participants, despite the chief investigator’s offers to complete the outcome measures with family carers over the phone or virtually. At three months follow-up, family carers completed the outcome measures between 13 to 27-weeks after the workshop. As a consequence, family carers with longer follow-up points may have had more time to consolidate or improve their ACT skills (e.g., Hartley et al., 2019), or the intervention gains may have reduced overtime (O’Brien, 2011). Additional research should aim to minimise the variation in the timing of data collection to draw more accurate conclusions about the effects of ACT within this population.

Additionally, this study used participant informed questionnaires which are likely to be affected by response biases (e.g., Chang et al., 2019), and thus may have limited the reliability and accuracy of the data. Another limitation was that most of the questionnaires used (e.g. DASS-21) were not specifically designed to be used within carer populations, which may have influenced the research findings (Drummond et al., 2019; Harvey et al., 2008). Future research should aim to develop or incorporate carer specific or adapted outcome measures (Blackledge, 2004).

Intervention

Due to time constraints related to the doctoral thesis, follow-up sessions were not offered in this study. Several family carers reported that additional and/or follow-up sessions would have been beneficial. In future, follow-up sessions should be offered (e.g. two months post-intervention) to boost treatment outcomes, consolidate participants' learning and/or address any misconceptions in relation to the ACT principles and techniques (Blackledge, 2004). These sessions could be used to identify and address any practical and cognitive barriers (e.g. fusion) to implementation, and to encourage participants to engage in valued-action (Blackledge, 2004; O'Brien, 2011; Zody, 2017). Although it is important to note that Zody (2017) offered a two-hour booster session one-month following the ACT workshop, however no parents attended. Future ACT outcome studies in this population should try to incorporate and overcome barriers to family carers attending follow-up sessions, and should investigate the effectiveness of these sessions (Zody, 2017).

This study did not assess family carers' understanding and retention of the ACT content. However, previous studies have assessed participants' understanding at post-intervention and follow-up (e.g., Drouillard, 2019; Lavelle et al., 2022). The inclusion of this data would have allowed the researcher to explore the relationships between carers' understanding and implementation of ACT and the intervention outcomes. Hence, the results of this study could be explained by issues related to participants' understanding and implementation of the ACT workshop, rather than the ACT model. For example, the qualitative feedback suggested that the carers may have had misconceptions about the ACT principles and techniques. Additional research should investigate participants' understanding of ACT and implementation of the ACT processes across multiple time points (Bacon, 2014).

It has been argued that one-day ACT workshops may not provide an adequate dose of ACT intervention (e.g., O'Brien, 2011). Compared to this study, several studies have used longer interventions (e.g., Blackledge and Hayes, 2006; Corti et al., 2018; Marino et al., 2021; Salimi et al., 2019) and multiple sessions (e.g. Lobato et al., 2022). Both of which provided participants with the opportunity to reflect and consolidate their learning between sessions (Drouillard, 2019). Although the shorter, one-day ACT intervention was recommended by a group of experts by experience and based on a review of other studies, this intervention design may have contributed to the lack of significant improvements reported in this study. Future research should examine the optimal doses and sessions of ACT for this carer population.

The ACT intervention protocol was specifically designed for this study and carer population, however it had not been implemented or evaluated prior to this study. Therefore, another ACT intervention protocol may have obtained different treatment outcomes. Similarly, it is possible that the intervention protocol was not tailored enough for this carer population (Blackledge, 2004). Future research should design and implement a more bespoke ACT intervention for this carer population (Blackledge, 2004). Similarly, some researchers have recommended combining ACT workshops for family carers with behavioural parent training (e.g., Blackledge, 2004). Whilst it was beyond the scope of this feasibility study, future research should compare the effects of ACT interventions alone or combined with behavioural parent training within this carer population.

Another limitation was that three carers were taking psychotropic medication from baseline to three months follow-up, which may have impacted the treatment outcomes. As previously mentioned, these family carers were subsequently included as they were experiencing carer-related stress and had asked to participate. Future studies may consider excluding family carers taking psychotropic medication to decrease the risk of co-intervention bias (e.g., Armijo-Olivo et al., 2022). Additionally, the group facilitators were aware of the study aims and thus may have unintentionally influenced the participants and study results (Drouillard, 2019). Lastly, this study did not train or include family carers as workshop co-facilitators due to time constraints. This approach has been used in other studies (Lunsky et al., 2018) and should be considered in future ACT research involving this carer population.

Overall, there were a number of limitations of this research, many of which were due to the practicalities and time constraints related to the doctoral thesis time frame. As the first ACT outcome study in this carer population, further research is required and should address these methodological and design limitations.

Implications

Clinical Implications

The results revealed that the majority of family carers were in the clinical range on at least one of the DASS-21 subscales. These findings further highlight the need to address the mental health needs and challenges within this carer population (Montgomery, 2015). Similarly, the majority of family carers reported that they had not received therapy in relation to carer related stress, highlighting the need to increase the availability of carer interventions (Montgomery, 2015). Positively, the findings indicated that ACT was highly acceptable for family carers of adults with IDs. Qualitative feedback indicated that the ACT workshop had several benefits for these family carers. On this basis, ACT should be considered as a possible psychosocial intervention for this carer population.

Additionally, incorporating ACT workshops may provide a low resource and low-cost intervention for this family carer population (Drouillard, 2019), particularly if services do not have the resources available to provide multiple or individual ACT sessions (Blackledge, 2004). Hence, this method of intervention may be feasible within child and adult LD services (Drouillard, 2019). Importantly, some carers commented that they would have benefitted from the ACT intervention when their relatives with IDs were children, suggesting that carer interventions within child LD services may be particularly helpful.

Moreover, ACT exercises could be adapted to fit a variety of topics relevant to family carers, such as managing behaviours of concern exhibited by their adult relative with IDs (e.g., Drouillard, 2019). Many of the recommendations from family carers to improve the ACT workshop can also be applied to other carer and/or ACT interventions both locally and nationally. Similarly, the ACT intervention protocol in this study could be used in the future, for example in ACT outcome studies and/or carer workshops. Nonetheless, future research is required to determine the feasibility, social acceptability and effectiveness of ACT for family carers of adults with IDs (Lobato et al., 2022). Based on extant literature, it is not currently possible to make conclusions about the most effective intervention for family carers of adults with IDs (Hastings and Beck, 2004). Prospective studies are required to compare the effects of different carer interventions, such psychoeducation, peer support groups and ACT (Corti et al., 2018).

Research Implications

To the best of the author’s knowledge, this was the first study to examine the effectiveness, feasibility and acceptability of ACT for family carers of adults with IDs. Therefore, the current research makes an important addition to the literature on ACT, IDs and family carer interventions within the UK. As a feasibility study, this study reports preliminary findings on the effects of ACT for family carers of individuals with IDs. This research also contributes to the literature on the mental health, positive aspects of caregiving, wellbeing, quality of life and demographics of this carer population.

It is important to write-up and/or publish non-significant findings to reduce the risk of publication bias (Ayorinde et al., 2020). Hence, the reporting of non-significant findings in this study may help to improve the validity and certainty of the ACT evidence base, and reduce the risk of overestimating the true effects of ACT (e.g., Murad et al., 2018). Also, the reporting and/or publishing of null findings may avoid unnecessary research duplication and reduce research ‘waste’ (Mlinarić et al., 2017; Polanin et al., 2016). Equally, it has been argued that it is important to replicate studies reporting non-significant findings as well as significant results (Pawel et al., 2024). Lastly, from an ethical perspective, the reporting of null findings promotes the transparency, integrity and trustworthiness of the research process (Roloff and Zyphur, 2019).

As most of the family carers attended the ACT workshop via a video conferencing platform, this study adds to the literature base on the remote delivery of ACT interventions (Fowler et al., 2021; Lavelle et al., 2022). Other studies have found online, guided self-help ACT interventions to be effective in improving psychological flexibility (e.g. Axenova, 2022; Kishita et al., 2022). Based on the caring responsibilities within this population, on-line and/or self-guided intervention formats may increase the accessibility of ACT. Future research should examine the effectiveness, acceptability and feasibility of online, self-guided ACT interventions for family carers of adults with IDs.

Theoretical Implications

This study did not aim to investigate the theoretical basis of ACT and therefore mediational and/or component analyses were not completed. Although the ACT intervention in this study did not result in significant improvements, the ACT model should not be disregarded when working with family carers of adults with IDs (Blackledge, 2004). Based on a systematic review of ACT mediation studies, it was reported that changes in psychological flexibility mediated improvements in mental health outcomes (Stockton et al., 2019). Similarly, research has demonstrated correlations between improvements in mental health outcomes of parents of children with ASCs (e.g. depression symptoms) and ACT processes (e.g., cognitive fusion and acceptance) (Blackledge and Hayes, 2006; Poddar et al., 2015). Hence, it could be argued that the non-significant changes in psychological flexibility and individual ACT processes found in this study could be explained by the non-significant changes in mental health outcomes. As such, these findings would be consistent with the ACT model of psychopathology (e.g., Blackledge, 2004).

Future research should investigate which individual ACT processes are most important for treatment gains within this family carer population (Gould et al., 2018). Additional research should also examine whether treatment outcomes are impacted by the order of ACT processes delivered within interventions (Gould et al., 2018). Overall, further research is warranted to elucidate the mediators (e.g. ACT processes) and moderators (e.g. type of family carer and severity of ID) of treatment outcomes within this carer population (Corti et al., 2018; Fung et al., 2018).

Policy Implications

The findings indicated that most family carers were supporting their relative with IDs in their family home, and all carers were providing social, emotional and practical support. The high levels of care provided in this family carer sample are consistent with existing criticisms of carer policies (Oulton and Heyman, 2009). More specifically, the Care Act (UK Government, 2014) has been criticised for increasingly shifting the responsibility from the welfare state onto family carers (e.g. Chard, 2022). As a result, it has been recommended that the current reliance on family carers should be decreased, and that policies should be developed to support both family carers and those being cared for (e.g., Pickard, 2001). Additional research and the provision of ACT groups within this carer population would be consistent with such recommendations.

Researcher Reflexivity

This section will be written in first person to convey my position in relation to this study and my own learning and reflections throughout the research process.

I originally became interested in this study for several reasons. Firstly, I had worked in learning disability services before starting my clinical psychology training. During this role, I worked alongside family carers to support their adult relatives with IDs. However, in line with the service model, I did not provide interventions to carers for their own personal mental health and wellbeing, which I felt was a gap in service provision. Secondly, I had grown up with a family relative diagnosed with a learning disability and therefore had witnessed some of the positive and negative aspects of informal caregiving. For these reasons, I felt enthusiastic about the opportunity to conduct research within this carer population.

Before clinical psychology training, I had started to develop an interest in ACT. I was particularly struck by some of the differences between ACT and CBT, including the emphasis in ACT on the workability of thoughts rather than the validity of thoughts in CBT. I found the concept of values and values-based action particularly helpful. For example, based on my personal values, I selected this thesis to act compassionately towards this family carer population and to challenge myself to learn more about ACT. In line with my values related to equality and fairness, I felt it was important to involve carers in the design of this study. Interestingly, I found it very difficult to find a local forum or support group specifically for this carer population. As a result, I felt further convinced of the need to improve access to carer support and interventions in this population.

Whilst recruiting participants, I developed a greater awareness of the day-to-day challenges and demands faced by this carer population. I was particularly struck by the fatigue and burnout reported by some family carers, and was shocked to hear that some carers were not able to gain even brief respite from their caring responsibilities. I felt a sense of injustice as there were several family carers who were interested in attending the ACT workshop, but were not able to as they did not have access to formal care arrangements for their relative with IDs. Consequently, I felt a sense of responsibility towards these family carers and felt committed to complete this study to the best of my ability.

Throughout the study there were a number of challenges to participant retention and data collection, many of which were due to factors outside of mine and the participant’s control (e.g. time constraints due to care demands). At times, I felt disheartened and powerless to help participants overcome these obstacles. During these times, I found it helpful to make space for unwanted feelings (e.g. frustration), and defuse from my own thoughts (e.g. stories about not being able to collect enough data). In many ways, continually revisiting the ACT processes as part of this study, reminded and encouraged me to implement my ACT skills.

Throughout the research process, I aimed to reflect on and be aware of my own position and any assumptions and past-experiences impacting the research. However, it is possible that my experiences, knowledge and interests may have influenced the study in several ways. Firstly, it is possible that my interest in ACT resulted in me choosing ACT over other psychological therapies for this carer population. Secondly, I may have been more inclined to select ACT exercises for the workshop which I have found to be more beneficial based on my past experiences. Thirdly, my personal experience of having an adult relative with a learning disability may have resulted in me exploring or focusing on certain experiences associated with caregiving, or selecting particular outcome measures. Overall, I enjoyed completing this study and feel it has developed both my research and clinical skills, particularly my understanding and application of ACT.

Conclusion

This study used a single group pretest-posttest design to evaluate the feasibility, acceptability and effects of a one-day ACT workshop for family carers of adults with IDs. This was the first known ACT intervention study within this carer population. Group-level analyses revealed that there was no significant differences on outcome measures across three time points. Similarly, there were limited improvements on outcome measures at individual levels. There were a number of possible explanations for these findings including the small sample size, insufficient statistical power, under-dosing of the ACT intervention, possible misconceptions and misapplications of the ACT principles, and further time needed for participants to consolidate and develop their ACT skills.

The ACT workshop for family carers was not deemed feasible as two of the four feasibility criteria were not met. It is possible that this finding could be explained by data collection challenges due to the care and personal demands of this carer population, which has been documented in comparable studies. Qualitative feedback on the social validity was mainly positive and indicated that all family carers felt that they had benefited at least ‘somewhat’ from the ACT intervention, which was consistent with findings from qualitative research. Nonetheless, it is possible that participants’ social validity feedback may have been influenced by social desirability bias.

There were a number of strengths of this study including the involvement of carers in the study design and intervention, the inclusion of social validity and treatment fidelity measures, the range of standardised and validated outcome measures, as well as the use of individual-level analyses and intervention adaptations. Alternatively, there were a number of limitations of the study including the absence of a control group and random allocation, use of self-report measures, and a lack of follow-up sessions, long-term follow-up data and limited diversity in the participant sample. Therefore, the results of this study should be interpreted in the context of these limitations. Recommendations were made to address the limitations of this study and gaps in the research literature. Finally, there were a number of clinical, research, theoretical and policy implications of this study.

References

Abbott, J. H. (2014). The distinction between randomized clinical trials (RCTs) and preliminary feasibility and pilot studies: what they are and are not. *Journal of Orthopaedic & Sports Physical Therapy*, *44*(8), 555-558. https://www.jospt.org/doi/10.2519/jospt.2014.0110

Ahmed, I., Sutton, A. J., & Riley, R. D. (2012). Assessment of publication bias, selection bias, and unavailable data in meta-analyses using individual participant data: A database survey. *BMJ: British Medical Journal*, *344*(7838), 1-10. https://doi.org/10.1136/bmj.d7762

Ali, A., Hassiotis, A., Strydom, A., & King, A. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*, 2122–2140 https://doi.org/10.1016/j.ridd.2012.06.013

Allik, H., Larsson, J. O., & Smedje, H. (2006). Insomnia in school-age children with Asperger syndrome or high-functioning autism. *BMC psychiatry*, *6*(1), 1-11. https://doi.org/10.1186/1471-244X-6-18

Armijo-Olivo, S., Mohamad, N., de Oliveira-Souza, A. I. S., de Castro-Carletti, E. M., Ballenberger, N., & Fuentes, J. (2022). Performance, Detection, Contamination, Compliance, and Cointervention Biases in Rehabilitation Research: What Are They and How Can They Affect the Results of Randomized Controlled Trials? Basic Information for Junior Researchers and Clinicians. *American Journal of Physical Medicine & Rehabilitation*, *101*(9), 864-878. https://doi.org/10.23736/s1973-9087.20.06427-8

Arnold, D. L., & McPherson, S. (2023). A systematic review on the mental health of parents of individuals with learning disabilities. *Human Systems*, *0*(0). https://doi.org/10.1177/26344041231217104

A-tjak, J. G., Davis, M. L., Morina, N., Powers, M. B., Smits, J. A., & Emmelkamp, P. M. (2015). A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems. *Psychotherapy and Psychosomatics*, *84*(1), 30-36. https://doi.org/10.1159/000365764

Audette, L. M., Hammond, M. S., & Rochester, N. K. (2020). Methodological issues with coding participants in anonymous psychological longitudinal studies. *Educational and Psychological Measurement*, *80*(1), 163-185. http://dx.doi.org/10.1177/0013164419843576

Avieli, H., Band-Winterstein, T., & Araten Bergman, T. (2019). Sibling relationships over the life course: Growing up with a disability. *Qualitative health research*, *29*(12), 1739-1750. https://doi.org/10.1177/1049732319837228

Axenova, K. (2022). *A Pilot Study of the Effectiveness and Feasibility of a Brief, Online, and Self-Guided Acceptance and Commitment Therapy Intervention for Intellectual and Developmental Disability Support Staff* [Doctoral Dissertation, University of Western Ontario]. ProQuest Dissertations and Theses Global. https://www.proquest.com/docview/2734703965?pq-origsite=gscholar&fromopenview=true&sourcetype=Dissertations%20&%20Theses

Ayhan, M. O., & Kavak Budak, F. (2021). The correlation between mindfulness and negative automatic thoughts in depression patients. *Perspectives in Psychiatric Care*, *57*(4), 1944-1949. https://doi.org/10.1111/ppc.12770

Ayorinde, A. A., Williams, I., Mannion, R., Song, F., Skrybant, M., Lilford, R. J., & Chen, Y. F. (2020). Publication and related biases in health services research: a systematic review of empirical evidence. *BMC Medical Research Methodology*, *20*(1), 1-12. https://doi.org/10.1186/s12874-020-01010-1

Bach, P., & Hayes, S. C. (2002). The use of acceptance and commitment therapy to prevent the rehospitalization of psychotic patients: a randomized controlled trial. *Journal of consulting and clinical psychology*, *70*(5), 1129. https://psycnet.apa.org/doi/10.1037/0022-006X.70.5.1129

Bacon, T., Farhall, J., & Fossey, E. (2014). The active therapeutic processes of acceptance and commitment therapy for persistent symptoms of psychosis: Clients' perspectives. *Behavioural and Cognitive Psychotherapy*, *42*(4), 402-420. https://doi.org/10.1017/S1352465813000209

Bahador, R. S., Farokhzadian, J., Rafiee Sarbijan Nasab, F., & Abbasi, M. (2023). Experiences of family caregivers of people with intellectual disabilities from rural areas in southeastern Iran: a qualitative study. *BMC psychiatry*, *23*(1), 613. https://doi.org/10.1186/s12888-023-05077-0

Banda, D. R., Carter, S. L., & Nguyen, T. (2022). A qualitative study of financial concerns of mothers' of adults with intellectual and developmental disabilities. *International Journal of Developmental Disabilities*, 1-8. https://doi.org/10.1080/20473869.2022.2152967

Banks, M. E. (2003). Disability in the family: a lifespan perspective. *Cultural Diversity and Ethnic Minority Psychology*, *9*(4), 367. https://psycnet.apa.org/doi/10.1037/1099-9809.9.4.367

Barajas, S., & Garra, L. (2014). Mindfulness and psychopathology: Adaptation of the Mindful Attention Awareness Scale (MAAS) in a Spanish sample. *Clínica y salud*, *25*(1), 49-56. https://doi.org/10.1016/S1130-5274(14)70026-X

Barnes-Holmes, Y., Barnes-Holmes, D., McHugh, L., & Hayes, S. C. (2004). Relational frame theory: Some implications for understanding and treating human psychopathology. *International journal of psychology and psychological therapy*, *4*, 355-375. https://www.redalyc.org/pdf/560/56040210.pdf

Beighton, C., Victor, C., Carey, I. M., Hosking, F., DeWilde, S., Cook, D. G., Manners, P., & Harris, T. (2019). 'I'm sure we made it a better study…': Experiences of adults with intellectual disabilities and parent carers of patient and public involvement in a health research study. *Journal of Intellectual Disabilities*, *23*(1), 78-96. https://doi.org/10.1177/1744629517723485

Beighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1255-1279. https://doi.org/10.1111/jar.12617

Benderix, Y., & Sivberg, B. (2007). Siblings' experiences of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families. *Journal of pediatric nursing*, *22*(5), 410-418. https://doi.org/10.1016/j.pedn.2007.08.013

Bigby, C. (2010). A five-country comparative review of accommodation support policies for older people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(1), 3-15. https://doi.org/10.1111/j.1741-1130.2010.00242.x

Blackledge, J. T. (2003). An introduction to relational frame theory: Basics and applications. *The Behavior Analyst Today*, *3*(4), 421–433. https://doi.org/10.1037/h0099997

Blackledge, J. T. (2004). *Using Acceptance and Commitment Therapy in the support of parents of children diagnosed with autism* [Doctoral dissertation, University of Nevada]. ProQuest Dissertations and Theses Global. https://www.proquest.com/pqdtglobal/docview/305163121/E9AEF3C69FCC4C6BPQ/2?accountid=10766&sourcetype=Dissertations%20&%20Theses

Blackledge, J. T., & Hayes, S. C. (2006). Using acceptance and commitment training in the support of parents of children diagnosed with autism. *Child & Family Behavior Therapy*, *28*(1), 1-18.

Blomquist, K. B. (2006). Health, education, work, and independence of young adults with disabilities. *Orthopedic Nursing*, *25*(3), 168-187. https://psycnet.apa.org/doi/10.1097/00006416-200605000-00005

Bloy, S. (2013). *Acceptance and commitment therapy for individuals with psychosis: A grounded theory analysis* [Doctoral dissertation, Canterbury Christ Church University]. ProQuest Dissertations and Theses Global. https://www.proquest.com/pqdtglobal/docview/2493113734/fulltextPDF/8B0D4BAA435458DPQ/1?accountid=10766&sourcetype=Dissertations%20&%20Theses

Bolderston, H., Gillanders, D. T., Turner, G., Taylor, H. C., & Coleman, A. (2019). The initial validation of a state version of the Cognitive Fusion Questionnaire. *Journal of Contextual Behavioral Science*, *12*, 207-215. https://doi.org/10.1016/j.jcbs.2018.04.002

Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., Waltz, T., & Zettle, R. D. (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire–II: A revised measure of psychological inflexibility and experiential avoidance. *Behavior therapy*, *42*(4), 676-688. https://doi.org/10.1016/j.beth.2011.03.007

Bourion-Bédès, S., Schwan, R., Epstein, J., Laprevote, V., Bédès, A., Bonnet, J. L., & Baumann, C. (2015a). Combination of classical test theory (CTT) and item response theory (IRT) analysis to study the psychometric properties of the French version of the Quality of Life Enjoyment and Satisfaction Questionnaire-Short Form (Q-LES-Q-SF). *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, *24*(2), 287–293. https://doi.org/10.1007/s11136-014-0772-y

Bourion-Bédès, S., Schwan, R., Laprevote, V., Bédès, A., Bonnet, J. L., & Baumann, C. (2015b). Differential item functioning (DIF) of SF-12 and Q-LES-Q-SF items among french substance users. *Health and quality of life outcomes*, *13*(1), 1-8. https://doi.org/10.1186/s12955-015-0365-7

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research a practical guide for beginners.* Sage publications.

Bray, L., Carter, B., Sanders, C., Blake, L., & Keegan, K. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling*, *100*(8), 1537-1543. https://doi.org/10.1016/j.pec.2017.03.004

Brinker, R. P., Seifer, R., & Sameroff, A. J. (1994). Relations among maternal stress, cognitive development, and early intervention in middle-and low-SES infants with developmental disabilities. *American journal of mental retardation: AJMR*, *98*(4), 463-480.

British Psychological Society (BPS). (2014). *Code of Human Research Ethics.* http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf

British Psychological Society (BPS). (2018). *Code of Ethics and Conduct.* https://cms.bps.org.uk/sites/default/files/2022-06/BPS%20Code%20of%20Ethics%20and%20Conduct.pdf

Brown, M., Macarthur, J., Higgins, A., & Chouliara, Z. (2019). Transitions from child to adult health care for young people with intellectual disabilities: a systematic review. *Journal of advanced nursing*, *75*(11), 2418-2434. https://doi.org/10.1111/jan.13985

Brown, K. W., & Ryan, R. M. (2003). The benefits of being present: mindfulness and its role in psychological well-being. *Journal of personality and social psychology*, *84*(4), 822. https://doi.org/10.1037/0022-3514.84.4.822

Burke, L. E., Wang, J., & Sevick, M. A. (2011). Self-monitoring in weight loss: a systematic review of the literature. *Journal of the American Dietetic Association*, *111*(1), 92-102. https://doi.org/10.1016/j.jada.2010.10.008

Busch, E. C. (2009). *Using acceptance and commitment therapy with parents of children with autism: The application of a theory*. [Doctoral dissertation, The Chicago School of Professional Psychology]. ProQuest Dissertations and Theses Global. https://www.proquest.com/docview/305144471?pq-origsite=gscholar&fromopenview=true&sourcetype=Dissertations%20&%20Theses

Byrne, G., Ghráda, Á. N., O'Mahony, T., & Brennan, E. (2021). A systematic review of the use of acceptance and commitment therapy in supporting parents. *Psychology and Psychotherapy: Theory, Research and Practice*, *94*(2), 378-407. https://doi.org/10.1111/papt.12282

Cameron, H., & Cooper, L. (2021). Fathers' experiences as carers for autistic children with learning disabilities. *British Journal of Learning Disabilities*, *49*(1), 13-22. https://doi.org/10.1111/bld.12349

Campbell, M., Katikireddi, S. V., Sowden, A., McKenzie, J. E., & Thomson, H. (2018). Improving Conduct and Reporting of Narrative Synthesis of Quantitative Data (ICONS-Quant): protocol for a mixed methods study to develop a reporting guideline. *BMJ open*, *8*(2), e020064. https://doi.org/10.1136/bmjopen-2017-020064

Campbell, M., McKenzie, J. E., Sowden, A., Katikireddi, S. V., Brennan, S. E., Ellis, S., Hartmann-Boyce, J., Ryan, R., Shepperd, S., Thomas, J., Welch, V., & Thomson, H. (2020). Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. *BMJ (Clinical research ed.)*, *368*, l6890. https://doi.org/10.1136/bmj.l6890

Caples, M., & Sweeney, J. (2011). Quality of life: a survey of parents of children/adults with an intellectual disability who are availing of respite care. *British Journal of Learning Disabilities*, *39*(1), 64-72. https://doi.org/10.1111/j.1468-3156.2010.00619.x

Cappa, K. A., Begle, A. M., Conger, J. C., Dumas, J. E., & Conger, A. J. (2011). Bidirectional relationships between parenting stress and child coping competence: Findings from the pace study. *Journal of child and family studies*, *20*, 334-342. https://doi.org/10.1007/s10826-010-9397-0

Casey, M. B., Smart, K. M., Segurado, R., Hearty, C., Gopal, H., Lowry, D., Flanagan, D., McCracken, L., & Doody, C. (2022). Exercise combined with Acceptance and Commitment Therapy compared with a standalone supervised exercise programme for adults with chronic pain: a randomised controlled trial. *Pain*, *163*(6), 1158-1171. https://doi.org/10.1097/j.pain.0000000000002487

Catak, P. D. (2012). The Turkish version of mindful attention awareness scale: preliminary findings. *Mindfulness*, *3*(1), 1-9. https://doi.org/10.1007/s12671-011-0072-3

Chambless, D. L., Baker, M. J., Baucom, D. H., Beutler, L. E., Calhoun, K. S., Crits-Christoph, P., Daiuto, A., DeRubeis, R., Detweiler, J., Haaga, D.A.F., Johnson, S.B., McCurry, S., Mueser, K.T., Pope, K.S., Sanderson, W.C., Shoham, V., Stickle, T., Williams, D.A., & Woody, S. R. (1998). Update on Empirically Validated Therapies, II. *Clinical Psychologist*, *51*(1). http://eft-academic-articles.s3.amazonaws.com/Chambless+1998+Update_on_Empirically_Validated_Therapies_II.pdf

Chang, E. M., Gillespie, E. F., & Shaverdian, N. (2019). Truthfulness in patient-reported outcomes: factors affecting patients' responses and impact on data quality. *Patient related outcome measures*, *10*, 171-186. https://doi.org/10.2147/PROM.S178344

Chard, K. A. (2022). *Exploring social inclusion and participation: assessing the impact of the Care Act (2014) on the social experience of caring* [Doctoral dissertation, University of Essex]. University of Essex Repository. https://repository.essex.ac.uk/33644/1/CHARD%20thesis_final.pdf

Chen, L., Zhong, M., Cao, X., Jin, X., Wang, Y., Ling, Y., Cen, W., Zhu, X., Yao, S., Zheng, X., & Yi, J. (2017). Stress and self-esteem mediate the relationships between different categories of perfectionism and life satisfaction. *Applied Research in Quality of Life, 12*(3), 593–605. https://doi.org/10.1007/s11482-016-9478-3

China, C., Hansen, L. B., Gillanders, D. T., & Benninghoven, D. (2018). Concept and validation of the German version of the Cognitive Fusion Questionnaire (CFQ-D). *Journal of Contextual Behavioral Science*, *9*, 30-35. https://doi.org/10.1016/j.jcbs.2018.06.003

Chua, J. Y. X., & Shorey, S. (2021). The Effect of Mindfulness-Based and Acceptance Commitment Therapy-Based Interventions to Improve the Mental Well-Being Among Parents of Children with Developmental Disabilities: A Systematic Review and Meta-Analysis. *Journal of Autism and Developmental Disorders*, *52*(6), 2770-2783. https://doi.org/10.1007/s10803-021-04893-1

Cluley, V. (2018). From "Learning disability to intellectual disability"—Perceptions of the increasing use of the term "intellectual disability" in learning disability policy, research and practice. *British Journal of Learning Disabilities*, *46(*1), 24-32. https://doi.org/10.1111/bld.12209

Coolican, H. (2018). *Research methods and statistics in psychology* (7th ed.). Routledge.

Cooper, S. A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC family practice*, *16*, 1-11. https://doi.org/10.1186/s12875-015-0329-3

Corti, C., Pergolizzi, F., Vanzin, L., Cargasacchi, G., Villa, L., Pozzi, M., & Molteni, M. (2018). Acceptance and commitment therapy-oriented parent-training for parents of children with autism. *Journal of Child and Family Studies*, *27*, 2887–2900. https://doi.org/10.1007/s10826-018-1123-3

Costa, J., Marôco, J., Pinto-Gouveia, J., & Galhardo, A. (2014). Validation of the Psychometric Properties of Acceptance and Action Questionnaire-II in Clinical and Nonclinical Groups of Portuguese Population. *International Journal of Psychology and Psychological Therapy*, *14*(3), 353-364. https://core.ac.uk/download/pdf/151539106.pdf

Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: evaluation of an intervention for at risk families. *Public health nursing (Boston, Mass.)*, *19*(4), 272–283. https://doi.org/10.1046/j.1525-1446.2002.19407.x

Cox, D. W., Motl, T. C., Bakker, A. M., & Lunt, R. A. (2018). Cognitive fusion and post-trauma functioning in veterans: Examining the mediating roles of emotion dysregulation. *Journal of Contextual Behavioral Science*, *8*, 1-7. https://doi.org/10.1016/j.jcbs.2018.02.002

Creswell, J.W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative and mixed method approaches* (5th ed.). Sage publications.

Cuijpers, P., Smit, F., Bohlmeijer, E., Hollon, S. D., & Andersson, G. (2010). Efficacy of cognitive-behavioural therapy and other psychological treatments for adult depression: meta-analytic study of publication bias. *The British journal of psychiatry : the journal of mental science*, *196*(3), 173–178. https://doi.org/10.1192/bjp.bp.109.066001

da Costa, B. R., Beckett, B., Diaz, A., Resta, N. M., Johnston, B. C., Egger, M., Juni, P., & Armijo-Olivo, S. (2017). Effect of standardized training on the reliability of the Cochrane risk of bias assessment tool: a prospective study. *Systematic reviews*, *6*(1), 1-8. https://doi.org/10.1186/s13643-017-0441-7

Davys, D., Mitchell, D., & Haigh, C. (2011). Adult sibling experience, roles, relationships and future concerns–a review of the literature in learning disabilities. *Journal of Clinical Nursing*, *20*(19-20), 2837-2853. https://doi.org/10.1111/j.1365-2702.2010.03530.x

Deacon, L., Nicholson, P., & Allen, K. (2020). *A Neoliberalist Solution for a Neoliberalist Problem: The Neoliberalist normalisation of psychosocial support for parent-carers.* CASS WokingPapers. https://sure.sunderland.ac.uk/id/eprint/12045/

Deng, Y. Q., Li, S., Tang, Y. Y., Zhu, L. H., Ryan, R., & Brown, K. (2012). Psychometric properties of the Chinese translation of the mindful attention awareness scale (MAAS). *Mindfulness*, *3*(1), 10-14. https://doi.org/10.1007/s12671-011-0074-1

Department of Health (2010) *Recognised, valued and supported: Next steps for the Carers Strategy*.http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122077

Dew, A., Collings, S., Dowse, L., Meltzer, A., & Smith, L. (2019). 'I don't feel like I'm in this on my own': Peer support for mothers of children with intellectual disability and challenging behaviour. *Journal of Intellectual Disabilities*, *23*(3), 344-358. https://doi.org/10.1177/1744629519843012

Dindo, L., Van Liew, J. R., & Arch, J. J. (2017). Acceptance and Commitment Therapy: A Transdiagnostic Behavioral Intervention for Mental Health and Medical Conditions. *Neurotherapeutics*, *14*(3), 546. https://doi.org/10.1007%2Fs13311-017-0521-3

Dionne, F., Gagnon, J., Balbinotti, M., Peixoto, E. M., Martel, M. E., Gillanders, D., & Monestès, J. L. (2016). "Buying Into Thoughts": Validation of a French Translation of the Cognitive Fusion Questionnaire. *Canadian Journal of Behavioural Science*, *48*(4), 278–285. https://doi.org/10.1037/cbs0000053

Drouillard, B. E. (2019). *Supporting Treatment Selection in Parents of Children with Autism Spectrum Disorder: An Educational Workshop with Acceptance and Commitment Training* [Doctoral dissertation, University of Windsor]. ProQuest Dissertations and Theses Global. https://www.proquest.com/docview/2322824738?pq-origsite=gscholar&fromopenview=true&sourcetype=Dissertations%20&%20Theses

Drummond, M., Johnston, B., & Quinn, T. J. (2019). Measuring the success of interventions for caregivers: a focussed systematic review. *Current opinion in supportive and palliative care*, *13*(4), 351. https://doi.org/10.1097%2FSPC.0000000000000461

Dunn, K., Rydzewska, E., Fleming, M., & Cooper, S. A. (2020). Prevalence of mental health conditions, sensory impairments and physical disability in people with co-occurring intellectual disabilities and autism compared with other people: a cross-sectional total population study in Scotland. *BMJ open*, *10*(4), e035280. https://doi.org/10.1136/bmjopen-2019-035280

Dymond, S., May, R. J., Munnelly, A., & Hoon, A. E. (2010). Evaluating the evidence base for relational frame theory: a citation analysis. *The Behavior analyst*, *33*(1), 97–117. https://doi.org/10.1007/BF03392206

Eisenbeck, N., & Szabó-Bartha, A. (2018). Validation of the Hungarian version of the Acceptance and Action Questionnaire-II (AAQ-II). *Journal of Contextual Behavioral Science*, *9*, 80-87. https://doi.org/10.1016/j.jcbs.2018.07.007

Elices, M., Tejedor, R., Pascual, J. C., Carmona, C., Soriano, J., & Soler, J. (2019). Acceptance and present-moment awareness in psychiatric disorders: Is mindfulness mood dependent?. *Psychiatry research*, *273*, 363-368. https://doi.org/10.1016/j.psychres.2019.01.041

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of intellectual disability Research*, *47*(4-5), 385-399. https://doi.org/10.1046/j.1365-2788.2003.00498.x

Endicott, J., Nee, J., Harrison, W., & Blumenthal, R. (1993). Quality of life enjoyment and satisfaction questionnaire: A new measure. *Psychopharmacology Bulletin*, *29*(2), 321–326.

Ezhumalai, S., Muralidhar, D., Dhanasekarapandian, R., & Nikketha, B. S. (2018). Group interventions. *Indian Journal of Psychiatry*, *60*(4), 514-21. https://doi.org/10.4103%2Fpsychiatry.IndianJPsychiatry_42_18

Fernández-Ávalos, M. I., Pérez-Marfil, M. N., Ferrer-Cascales, R., Cruz-Quintana, F., Clement-Carbonell, V., & Fernández-Alcántara, M. (2020). Quality of life and concerns in parent caregivers of adult children diagnosed with intellectual disability: A qualitative study. *International Journal of Environmental Research and Public Health*, *17*(22), 8690. https://doi.org/10.3390/ijerph17228690

Fledderus, M., Oude Voshaar, M. A., Ten Klooster, P. M., & Bohlmeijer, E. T. (2012). Further evaluation of the psychometric properties of the Acceptance and Action Questionnaire–II. *Psychological assessment*, *24*(4), 925. https://psycnet.apa.org/doi/10.1037/a0028200

Flynn, M. K., Hernandez, J. O., Hebert, E. R., James, K. K., & Kusick, M. K. (2018). Cognitive fusion among hispanic college students: Further validation of the Cognitive Fusion Questionnaire. *Journal of contextual behavioral science*, *7*, 29-34. https://doi.org/10.1016/j.jcbs.2017.11.003

Forsythe, L. P., Carman, K. L., Szydlowski, V., Fayish, L., Davidson, L., Hickam, D. H., Hall, C., Bhat, G., Neu, D., Steward, L., Jalowsky, M., Aronson, N., & Anyanwu, C. U. (2019). Patient engagement in research: early findings from the Patient-Centered Outcomes Research Institute. *Health Affairs*, *38*(3), 359-367. https://doi.org/10.1377/hlthaff.2018.05067

Fowler, N. R., Judge, K. S., Lucas, K., Gowan, T., Stutz, P., Shan, M., Wilhelm, L., Parry, T., & Johns, S. A. (2021). Feasibility and acceptability of an acceptance and commitment therapy intervention for caregivers of adults with Alzheimer's disease and related dementias. *BMC geriatrics*, *21*(1), 1-10. https://doi.org/10.1186/s12877-021-02078-0

Francis, A. W., Dawson, D. L., & Golijani-Moghaddam, N. (2016). The development and validation of the Comprehensive assessment of Acceptance and Commitment Therapy processes (CompACT). *Journal of Contextual Behavioral Science*, *5*(3), 134-145. https://doi.org/10.1016/j.jcbs.2016.05.003

Fredrickson, B. L., Cohn, M. A., Coffey, K. A., Pek, J., & Finkel, S. M. (2008). Open hearts build lives: Positive emotions, induced through loving-kindness meditation, build consequential personal resources. *Journal of Personality And Social Psychology*, *95*(5), 1045-1062. https://psycnet.apa.org/doi/10.1037/a0013262

Frey, K. S., Greenberg, M. T., & Fewell, R. R. (1989). Stress and coping among parents of handicapped children: a multidimensional approach. *American Journal of Mental Retardation: AJMR*, *94*(3), 240-249.

Fung, K., Lake, J., Steel, L., Bryce, K., & Lunsky, Y. (2018). ACT processes in group intervention for mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(8), 2740–2747. https://doi.org/10.1007/s10803-018-3525-x

Futschik, A., Taus, T., & Zehetmayer, S. (2019). An omnibus test for the global null hypothesis. *Statistical methods in medical research*, *28*(8), 2292-2304. https://doi.org/10.1177/0962280218768326

Gagnier, J. J., Moher, D., Boon, H., Beyene, J., & Bombardier, C. (2012). Investigating clinical heterogeneity in systematic reviews: a methodologic review of guidance in the literature. *BMC medical research methodology*, *12*(1), 1-15. https://doi.org/10.1186/1471-2288-12-111

Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of pediatric psychology*, *33*(10), 1129-1136. https://doi.org/10.1093/jpepsy/jsn040

Gallagher, S., & Whiteley, J. (2013). The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children's challenging behaviours. *Journal of health psychology*, *18*(9), 1220-1231. https://doi.org/10.1177/1359105312464672

Garcia, Y., Keller-Collins, A., Andrews, M., Kurumiya, Y., Imlay, K., Umphrey, B., & Foster, E. (2022). Systematic review of acceptance and commitment therapy in individuals with neurodevelopmental disorders, caregivers, and staff. *Behavior Modification*, *46*(5), 1236-1274. https://doi.org/10.1177/01454455211027301

Garzon, L. (2012). *Acceptance and Commitment Therapy (ACT) as an Alternative for Reducing Psychological Distress Experienced by Latino Parents of Children with Autism: A Pilot Study* [Doctoral dissertation, The Chicago School of Professional Psychology]. ProQuest Dissertations and Theses Global. https://www.proquest.com/docview/1313771621/fulltextPDF/C2776D394A2247F0PQ/1?accountid=10766&sourcetype=Dissertations%20&%20Theses

Gaudiano, B. A. (2011). Evaluating acceptance and commitment therapy: An analysis of a recent critique.International *Journal of Behavioral Consultation and Therapy, 7*(1), 54–65. https://doi.org/10.1037/h0100927

Gauthier-Boudreault, C., Beaudoin, A. J., Gallagher, F., & Couture, M. (2019). Scoping review of social participation of individuals with profound intellectual disability in adulthood: What can I do once I finish school?. *Journal of Intellectual & Developmental Disability*, *44*(2), 248-260. https://doi.org/10.3109/13668250.2017.1310810

Gilbert, B. D., & Christopher, M. S. (2010). Mindfulness-Based Attention as a Moderator of the Relationship Between Depressive Affect and Negative Cognitions. *Cognitive Therapy and Research*, *34*(6), 514. https://doi.org/10.1007/s10608-009-9282-6

Gillanders, D. T., Bolderston, H., Bond, F. W., Dempster, M., Flaxman, P. E., Campbell, L., Kerr, S., Tansey, L., Noel, P., Ferenbach, C., Masley, S., Roach, L., Lloyd, J., May, L., Clarke, S., & Remington, B. (2014). The development and initial validation of the cognitive fusion questionnaire. *Behavior therapy*, *45*(1), 83-101. https://doi.org/10.1016/j.beth.2013.09.001

Glidden, L. M., & Schoolcraft, S. A. (2003). Depression: Its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research*, *47*(4-5), 250-263. https://doi.org/10.1046/j.1365-2788.2003.00487.x

Gloster, A. T., Walder, N., Levin, M. E., Twohig, M. P., & Karekla, M. (2020). The empirical status of acceptance and commitment therapy: A review of meta-analyses. *Journal of Contextual Behavioral Science, 18*, 181-192. https://doi.org/10.1016/j.jcbs.2020.09.009

González-Blanch, C., Medrano, L. A., O'Sullivan, S., Bell, I., Nicholas, J., Chambers, R., Gleeson, J.F., & Alvarez-Jimenez, M. (2022). Psychometric properties of the Mindful Attention Awareness Scale (MAAS) in a first-episode psychosis sample. *Psychological Assessment*, *34*(2), 188. https://psycnet.apa.org/doi/10.1037/pas0001077

Good, G., Hollis-English, A., Attwell, A., Dickson, A., Gibbs, A., Gordon, J., & Taylor, J. (2017). Social-model mothers: Disability, advocacy, and activism. *Counterfutures*, *4*, 107-135. https://ieag.org.nz/assets/Uploads/MothersofDisabled.pdf

Gould, E. R., Tarbox, J., & Coyne, L. (2018). Evaluating the effects of acceptance and commitment training on the overt behavior of parents of children with autism. *Journal of Contextual Behavioral Science*, *7*, 81–88. https://doi.org/10.1016/j.jcbs.2017.06.003

Grant, G., & Whittell, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the lifespan. Journal of *Applied Research in Intellectual Disabilities*, *13(*4), 256-275. https://doi.org/10.1046/j.1468-3148.2000.00035.x

Gregg, J. A. (2004). *A randomized controlled effectiveness trial comparing patient education with and without acceptance and commitment therapy for type 2 diabetes self-management* [Doctoral Dissertation, University of Nevada, Reno]. ProQuest Dissertations and Theses Global. https://www.proquest.com/docview/305163704?pq-origsite=gscholar&fromopenview=true&sourcetype=Dissertations%20&%20Theses

Gregório, S., & Pinto-Gouveia, J. (2013). Mindful Attention and Awareness: Relationships with Psychopathology and Emotion Regulation. *Spanish Journal of Psychology*, *16*(e79), 1-10. https://doi.org/10.1017/sjp.2013.79

Gresham, F. M., Dart, E. H., & Collins, T. A. (2017). Generalizability of multiple measures of treatment integrity: Comparisons among direct observation, permanent products, and self-report. *School Psychology Review*, *46*(1), 108-121. https://doi.org/10.1080/02796015.2017.12087606

Grey, J. M., Totsika, V., & Hastings, R. P. (2018). Physical and psychological health of family carers co-residing with an adult relative with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *31*, 191-202. https://doi.org/10.1111/jar.12353

Grix, J. (2019). *The Foundations of Reseach*, (3rd ed.). Red Globe Press.

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Sage Publications

Guidi J., Brakemeier E. L., Bockting C. L. H., Cosci F., Cuijpers P., Jarrett R. B., Linden M., Marks I., Peretti C. S., Rafanelli C., Rief W., Schneider S., Schnyder U., Sensky T., Tomba E., Vazquez C., Vieta E., Zipfel S., Wright J. H., Fava G. A. (2018). Methodological recommendations for trials of psychological interventions. *Psychotherapy and psychosomatics*, *87*(5), 276-284. https://doi.org/10.1159/000490574

Gur, A., & Reich, A. (2023). Psychological flexibility of parents of children with disabilities: A systematic literature review. *Research in developmental disabilities*, *136*, 104490. https://doi.org/10.1016/j.ridd.2023.104490

Hahs, A. D., Dixon, M. R., & Paliliunas, D. (2019). Randomized controlled trial of a brief acceptance and commitment training for parents of individuals diagnosed with autism spectrum disorders. *Journal of Contextual Behavioral Science*, *12*, 154–159. https://doi.org/10.1016/j.jcbs.2018.03.002

Han, A., Yuen, H. K., & Jenkins, J. (2021). Acceptance and commitment therapy for family caregivers: A systematic review and meta-analysis. *Journal of Health Psychology*, *26*(1), 82-102. https://doi.org/10.1177/1359105320941217

Harris, R. (2009). *ACT Made Simple: An Easy-To-Read Primer on Acceptance and Commitment Therapy*. New Harbinger Publications.

Harris, R. (2019). *ACT made simple: An easy-to-read primer on acceptance and commitment therapy*. (2nd ed.). New Harbinger Publications.

Harrison, M. (2012). *A qualitative service evaluation of the usefulness of a group based acceptance and commitment therapy programme for chronic pain* [Doctoral dissertation, University of Hertfordshire]. University of Hertfordshire Research Archive. https://core.ac.uk/reader/9553050

Hartley, M., Dorstyn, D., & Due, C. (2019). Mindfulness for Children and Adults with Autism Spectrum Disorder and Their Caregivers: A Meta-analysis. *Journal of Autism and Developmental Disorders*, *49*(10), 4306-4320. https://doi.org/10.1007/s10803-019-04145-3

Harvey, K., Catty, J., Langman, A., Winfield, H., Clement, S., Burns, E., White, S., & Burns, T. (2008). A review of instruments developed to measure outcomes for carers of people with mental health problems. *Acta Psychiatrica Scandinavica*, *117*(3), 164-176. https://doi.org/10.1111/j.1600-0447.2007.01148.x

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of intellectual disability research*, *49*(6), 405-418. https://doi.org/10.1111/j.1365-2788.2005.00673.x

Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of child psychology and psychiatry*, *45*(8), 1338-1349. https://doi.org/10.1111/j.1469-7610.2004.00357.x

Hatton, C. (2017). Living arrangements of adults with learning disabilities across the UK. *Tizard Learning Disability Review*, *22*(1), 43-50. https://doi.org/10.1108/TLDR-11-2016-0040

Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behavior therapy*, *35*(4), 639-665. https://doi.org/10.1016/S0005-7894(04)80013-3

Hayes, S. C., Barnes-Holmes, D., & Roche, B. (2003). Behavior analysis, relational frame theory, and the challenge of human language and cognition: A reply to the commentaries on Relational Frame Theory: A Post-Skinnerian Account of Human Language and Cognition. *The Analysis of Verbal Behavior*, *19*, 39-54. https://doi.org/10.1007/BF03392981

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour research and therapy*, *44*(1), 1-25. https://doi.org/10.1016/j.brat.2005.06.006

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). Acceptance and commitment therapy: An experiential approach to behavior change. Guilford Press.

Hayes, S. C., Villatte, M., Levin, M., & Hildebrandt, M. (2011). Open, aware, and active: contextual approaches as an emerging trend in the behavioral and cognitive therapies. *Annual Review of Clinical Psychology*, *7*, 141-168. https://doi.org/10.1146/annurev-clinpsy-032210-104449

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British journal of clinical psychology*, *44*(2), 227-239. http://dx.doi.org/10.1348/014466505X29657

Hildebrand, M. W., Host, H. H., Binder, E. F., Carpenter, B., Freedland, K. E., Morrow-Howell, N., Baum, C. M., Doré, P., & Lenze, E. J. (2012). Measuring treatment fidelity in a rehabilitation intervention study. *American journal of physical medicine & rehabilitation/Association of Academic Physiatrists*, *91*(8), 715. https://doi.org/10.1097%2FPHM.0b013e31824ad462

Hilgeman, M. M., Allen, R. S., DeCoster, J., & Burgio, L. D. (2007). Positive aspects of caregiving as a moderator of treatment outcome over 12 months. *Psychology and aging*, *22*(2), 361. https://psycnet.apa.org/doi/10.1037/0882-7974.22.2.361

Hofmann, S. G., & Asmundson, G. J. (2008). Acceptance and mindfulness-based therapy: new wave or old hat?. *Clinical psychology review*, *28*(1), 1-16. https://doi.org/10.1016/j.cpr.2007.09.003

Hope, M. L., Page, A. C., & Hooke, G. R. (2009). The value of adding the Quality of Life Enjoyment and Satisfaction Questionnaire to outcome assessments of psychiatric inpatients with mood and affective disorders. *Quality of Life Research*, *18*(5), 647-655. http://dx.doi.org/10.1007/s11136-009-9478-y

Hsu, L. M. (1996). On the identification of clinically significant client changes: Reinterpretation of Jacobson's cut scores. *Journal of Psychopathology and Behavioral Assessment*, *18*(4), 371-385. http://dx.doi.org/10.1007/BF02229141

Jackson, J. L., & Kuriyama, A. (2019). How often do systematic reviews exclude articles not published in English?. *Journal of general internal medicine*, *34*(8), 1388-1389. https://doi.org/10.1007/s11606-019-04976-x

Jacobson, N. S., & Truax, P. (1991). Clinical significance: A statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology*, *59*(1), 12. https://doi.org/10.1037//0022-006x.59.1.12

Järvelä-Reijonen, E., Puttonen, S., Karhunen, L., Sairanen, E., Laitinen, J., Kolehmainen, M., Pihlajamäki, J., Kujala, U., Korpela, R., Ermes, M., Lappalainen, R., & Kolehmainen, M. (2020). The Effects of Acceptance and Commitment Therapy (ACT) Intervention on Inflammation and Stress Biomarkers: a Randomized Controlled Trial. *International journal of behavioral medicine*, *27*(5), 539. https://doi.org/10.1007/s12529-020-09891-8

Jin, X., Wong, C. L., Li, H., Chen, J., Chong, Y. Y., & Bai, Y. (2021). Acceptance and Commitment Therapy for psychological and behavioural changes among parents of children with chronic health conditions: A systematic review. *Journal of Advanced Nursing*, *77*(7), 3020-3033. https://doi.org/10.1111/jan.14798

Joekar, S., Farid, A. A., Birashk, B., Gharraee, B., & Mohammadian, M. (2016). Effectiveness of acceptance and commitment therapy in the support of parents of children with high-functioning Autism. *International Journal of Humanities and Cultural Studies*, *2*(4), 2763–2772. http://ijhcs.com/index.php/ijhcs/article/view/2524/2792

Jogdand, A. M., & Magar, A. A. (2020). The effect of group-based acceptance and commitment therapy on mental health of parents of children with autism spectrum disorder. *International Journal of Indian Psychology*, *8*(2), 1332-1338. https://ijip.in/wp-content/uploads/2020/07/18.01.152.20200802.pdf

Johns, L. C., Oliver, J. E., Khondoker, M., Byrne, M., Jolley, S., Wykes, T., Joseph, C., Butler, L., Craig, T., & Morris, E. M. (2016). The feasibility and acceptability of a brief Acceptance and Commitment Therapy (ACT) group intervention for people with psychosis: the ‘ACT for life’study. *Journal of behavior therapy and experimental psychiatry*, *50*, 257-263. https://doi.org/10.1016/j.jbtep.2015.10.001

José Quintero, P. S., Rodríguez Biglieri, R., Etchezahar, E., & Gillanders, D. T. (2022). The Argentinian version of the cognitive fusion questionnaire: Psychometric properties and the role of cognitive fusion as a predictor of pathological worry. *Current Psychology*, *41*(5), 2546-2557. https://doi.org/10.1007/s12144-020-00767-4

Joseph, S., Becker, S., Elwick, H., & Silburn, R. (2012). Adult carers quality of life questionnaire (AC-QoL): development of an evidence-based tool. *Mental Health Review Journal*, *17*(2), 57-69. https://doi.org/10.1108/13619321211270380

Juarascio, A. S., Forman, E. M., & Herbert, J. D. (2010). Acceptance and commitment therapy versus cognitive therapy for the treatment of comorbid eating pathology. *Behavior modification*, *34*(2), 175-190. https://doi.org/10.1177/0145445510363472

Juvin, J., Sadeg, S., Julien-Sweerts, S., & Zebdi, R. (2021). A Systematic Review: Acceptance and Commitment Therapy for the Parents of Children and Adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *52*, 124-141. https://doi.org/10.1007/s10803-021-04923-y

Kang, H. (2021). Sample size determination and power analysis using the G* Power software. *Journal of Educational Evaluation for Health Professions*, *18*(1), 17-0. http://doi.org/10.3352/jeehp.2021.18.17

Karekla, M., & Michaelides, M. P. (2017). Validation and invariance testing of the Greek adaptation of the Acceptance and Action Questionnaire-II across clinical vs. nonclinical samples and sexes. *Journal of Contextual Behavioral Science*, *6*(1), 119-124. https://doi.org/10.1016/j.jcbs.2016.11.006

Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2012). Scale for positive aspects of caregiving experience: development, reliability, and factor structure. *East Asian Archives of Psychiatry*, *22*(2), 62-69.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of advanced nursing*, *34*(5), 582-592. https://doi.org/10.1046/j.1365-2648.2001.01787.x

Kelly, P., Kahlmeier, S., Götschi, T., Orsini, N., Richards, J., Roberts, N., Scarborough, C., & Foster, C. (2014). Systematic review and meta-analysis of reduction in all-cause mortality from walking and cycling and shape of dose response relationship. *International journal of behavioral nutrition and physical activity*, *11*(1), 1-15. https://doi.org/10.1186/s12966-014-0132-x

Kishita, N., Gould, R. L., Farquhar, M., Contreras, M., Van Hout, E., Losada, A., Cabrera, I., Hornberger, M., Richmond, E., & McCracken, L. M. (2022). Internet-delivered guided self-help acceptance and commitment therapy for family carers of people with dementia (iACT4CARERS): a feasibility study. *Aging & Mental Health*, *26*(10), 1933-1941. https://doi.org/10.1080/13607863.2021.1985966

Knight, K. (2013). The changing face of the 'good mother': trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society*, *28*(5), 660-673. https://doi.org/10.1080/09687599.2012.732540

Kowalkowski, J. D. (2012). *The impact of a group-based acceptance and commitment therapy intervention on parents of children diagnosed with an autism spectrum disorder*. [Doctoral dissertation, Eastern Michigan University]. ProQuest Dissertations and Theses Global. https://www.proquest.com/docview/1038971125/2F35A18960A54270PQ/1?accountid=10766&sourcetype=Dissertations%20&%20Theses

Kruithof, K., Olsman, E., Nieuwenhuijse, A., & Willems, D. (2021). "I hope I'll outlive him": A qualitative study of parents' concerns about being outlived by their child with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*, *47*(1), 1-11. https://doi.org/10.3109/13668250.2021.1920377

Kruithof, K., Willems, D., Nieuwenhuijse, A., & Olsman, E. (2022). Care and support for persons with profound intellectual and multiple disabilities without parents: A qualitative exploration. *Research in Developmental Disabilities*, *130*, 104334. https://doi.org/10.3109/13668250.2021.1920377

Lavelle, J., Storan, D., Eswara Murthy, V., De Dominicis, N., Mulcahy, H. E., & McHugh, L. (2022). Brief and Telehealth Acceptance and Commitment Therapy (ACT) Interventions for Stress in Inflammatory Bowel Disease (IBD): A Series of Single

Case Experimental Design (SCED) Studies. *Journal of clinical medicine*, *11*(10), 2757. https://doi.org/10.3390/jcm11102757

Lee, C. E., & Burke, M. M. (2018). Caregiving roles of siblings of adults with intellectual and developmental disabilities: A systematic review. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(3), 237-246. https://doi.org/10.1111/jppi.12246

Lee, Y. H. (2019). Strengths and limitations of meta-analysis. *Korean Journal of Medicine*, *94*(5), 391-395. https://doi.org/10.3904/kjm.2019.94.5.391

Leung, C. Y. S., & Li-Tsang, C. W. P. (2003). Quality of life of parents who have children with disabilities. *Hong Kong journal of occupational therapy*, *13*(1), 19-24. https://doi.org/10.1016/S1569-1861(09)70019-1

Levin, M. E., Haeger, J. A., Pierce, B. G., & Twohig, M. P. (2017). Web-based acceptance and commitment therapy for mental health problems in college students: A randomized controlled trial. *Behavior Modification*, *41*(1), 141-162. https://doi.org/10.1177/0145445516659645

Levin, M. E., Hildebrandt, M. J., Lillis, J., & Hayes, S. C. (2012). The impact of treatment components suggested by the psychological flexibility model: A meta-analysis of laboratory-based component studies. *Behavior therapy*, *43*(4), 741-756. https://doi.org/10.1016/j.beth.2012.05.003

Llewellyn, G., McConnell, D., Gething, L., Cant, R., & Kendig, H. (2010). Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. *Research in developmental disabilities*, *31*(6), 1176-1186. https://doi.org/10.1016/j.ridd.2010.08.003

Lloyd, T., & Hastings, R. P. (2009). Parental locus of control and psychological well-being in mothers of children with intellectual disability. *Journal of Intellectual and Developmental Disability*, *34*(2), 104-115. https://doi.org/10.1080/13668250902862074

Lobato, D., Montesinos, F., Polín, E., & Cáliz, S. (2022). Acceptance and Commitment Training Focused on Psychological Flexibility for Family Members of Children with Intellectual Disabilities. *International Journal of Environmental Research and Public Health*, *19*(21), 13943. https://doi.org/10.3390%2Fijerph192113943

Luckasson, R., Ford, M. E., McMillan, E. D., Misilo Jr, F. M., & Nygren, M. A. (2017). Intellectual disability policy as developed, expressed, and evaluated in AAIDD/The Arc joint statements: The role of organization position statements. *Intellectual and*

Developmental Disabilities, *55*(4), 269-275. https://doi.org/10.1352/1934-9556-55.4.269

Lundahl, B., Risser, H. J., & Lovejoy, M. C. (2006). A meta-analysis of parent training: Moderators and follow-up effects. *Clinical psychology review*, *26*(1), 86-104. https://doi.org/10.1016/j.cpr.2005.07.004

Lunsky, Y., Fung, K., Lake, J., Steel, L., & Bryce, K. (2017). Evaluation of acceptance and commitment therapy (ACT) for mothers of children and youth with autism spectrum disorder. *Mindfulness*, *9*(4), 1110–1116. https://doi.org/10.1007/s12671-017-0846-3

Luoma, J. B., Hayes, S. C., & Walser, R. D. (2007). *Learning ACT: An acceptance & commitment therapy skills-training manual for therapists*. New Harbinger Publications.

Luque-Reca, O., Gillanders, D., Catala, P., & Peñacoba, C. (2021). Psychometric properties of the Cognitive Fusion Questionnaire in females with fibromyalgia. *Current Psychology*, 1-11. https://doi.org/10.1007/s12144-021-02214-4

MacDonald, E. E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological acceptance mediates the impact of the behaviour problems of children with intellectual disability on fathers' psychological adjustment. *Journal of Applied Research in Intellectual Disabilities*, *23*(1), 27-37. https://doi.org/10.1111/j.1468-3148.2009.00546.x

MacKillop, J., & Anderson, E. J. (2007). Further Psychometric Validation of the Mindful Attention Awareness Scale (MAAS). *Journal of Psychopathology and Behavioral Assessment*, *29*(4), 289-293. https://doi.org/10.1007/s10862-007-9045-1

Mackinnon D. P. (2011). Integrating Mediators and Moderators in Research Design. *Research on social work practice*, *21*(6), 675–681. https://doi.org/10.1177/1049731511414148

Magnacca, C., Thomson, K., & Marcinkiewicz, A. (2021). Acceptance and Commitment Therapy for Caregivers of Children with Neurodevelopmental Disabilities: a Systematic Review. *Current Developmental Disorders Reports*, *8*, 152–160. https://doi.org/10.1007/s40474-021-00228-y

Mak, W. W., & Cheung, R. Y. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of applied research in intellectual disabilities*, *21*(6), 532-545. https://doi.org/10.1111/j.1468-3148.2008.00426.x

Malo, R., Acier, D., & Bulteau, S. (2022). Psychological Flexibility: Toward a Better Understanding of a Key Concept. *Trends in Psychology*, 1-26. https://doi.org/10.1007/s43076-022-00188-1

Marino F., Failla C., Chilà P., Minutoli R., Puglisi A., Arnao A. A., Pignolo L., Presti G., Pergolizzi F., Moderato P., Tartarisco G., Ruta L., Vagni D., Cerasa A., & Pioggia G. (2021). The Effect of Acceptance and Commitment Therapy for Improving Psychological Well-Being in Parents of Individuals with Autism Spectrum Disorders: A Randomized Controlled Trial. *Brain Sciences*, *11*(7), 880. https://doi.org/10.3390/brainsci11070880

Mash, E. J., & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of clinical child psychology*, *19*(4), 313-328. https://doi.org/10.1207/s15374424jccp1904_3

Maurer, M., Rikki, M., Tandrea, H. B., Amolegbe, A., Carman, K. L., Forsythe, L., Mosbacher, R., Lesch, J. K., & Woodward, K. (2022). Understanding the Influence and Impact of Stakeholder Engagement in Patient-centered Outcomes Research: a Qualitative Study. *Journal of General Internal Medicine*, *37*(1), 6-13. https://doi.org/10.1007/s11606-021-07104-w

McConnell, D., & Savage, A. (2015). Stress and Resilience Among Families Caring for Children with Intellectual Disability: Expanding the Research Agenda. *Health*, *6*(7), 8. https://doi.org/10.1007/s40474-015-0040-z

McPherson, S., & Oute, J. (2021). Responsibilisation of caregivers in depression: the limitations of policy-based evidence. *Social theory & health*, *19*, 347-361. https://doi.org/10.1057/s41285-020-00136-y

Merriman, K., Burke, T., & O'Reilly, G. (2020). A systematic review of the effectiveness and efficacy of clinician-led psychological interventions for parents of children with ASD. *Research in Autism Spectrum Disorders*, *76*, 101584. https://doi.org/10.1016/j.rasd.2020.101584

Mertens, D. M. (2015). *Research and evaluation in education and psychology* (4th ed.). Sage Publications.

Meyer, E. C., Morissette, S. B., Kimbrel, N. A., Kruse, M. I., & Gulliver, S. B. (2013). Acceptance and Action Questionnaire—II scores as a predictor of posttraumatic stress disorder symptoms among war veterans. *Psychological Trauma: Theory, Research, Practice, and Policy*, *5*(6), 521. https://psycnet.apa.org/doi/10.1037/a0030178

Minozzi, S., Cinquini, M., Gianola, S., Castellini, G., Gerardi, C., & Banzi, R. (2019). Risk of bias in nonrandomized studies of interventions showed low inter-rater reliability and challenges in its application. *Journal of clinical epidemiology*, *112*, 28-35. https://doi.org/10.1016/j.jclinepi.2019.04.001

Minozzi, S., Cinquini, M., Gianola, S., Gonzalez-Lorenzo, M., & Banzi, R. (2020). The revised Cochrane risk of bias tool for randomized trials (RoB 2) showed low interrater reliability and challenges in its application. *Journal of Clinical Epidemiology*, *126*, 37-44. https://doi.org/10.1016/j.jclinepi.2020.06.015

Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in developmental disabilities*, *89*, 10-21. https://doi.org/10.1016/j.ridd.2019.03.001

Mlinarić, A., Horvat, M., & Šupak Smolčić, V. (2017). Dealing with the positive publication bias: Why you should really publish your negative results. *Biochemia medica*, *27*(3), 447-452. https://doi.org/10.11613/BM.2017.030201

Montgomery, D. (2015). *The effects of acceptance and commitment therapy on parents of children diagnosed with autism.* [Doctoral Dissertation, Walden University] ProQuest Dissertations and Theses Global. https://www.proquest.com/docview/1685392782/C67606A8E90948A0PQ/1?accountid=10766&sourcetype=Dissertations%20&%20Theses

Morley S, Dowzer C. (2014). *Manual for the Leeds Reliable Change Indicator: Simple Excel (tm) applications for the analysis of individual patient and group data.* University of Leeds, Leeds, UK. https://dclinpsych.leeds.ac.uk/wp-content/uploads/sites/26/2018/09/Manual-for-Leeds-RCI-CSC-calculators.pdf

Mulvany, F., Barron, S., & McConkey, R. (2007). Residential provision for adult persons with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, *20*(2), 70-76. https://doi.org/10.1111/j.1468-3148.2006.00306.x

Munder, T., & Barth, J. (2018). Cochrane's risk of bias tool in the context of psychotherapy outcome research. *Psychotherapy Research*, *28*(3), 347-355. https://doi.org/10.1080/10503307.2017.1411628

Murad, M. H., Chu, H., Lin, L., & Wang, Z. (2018). The effect of publication bias magnitude and direction on the certainty in evidence. *BMJ evidence-based medicine*, *23*(3), 84-86. https://doi.org/10.1136/bmjebm-2018-110891

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: care, health and development*, *33*(2), 180-187. https://doi.org/10.1111/j.1365-2214.2006.00644.x

Murrell, A.R. , Schmalz, J., Mitchell, P.R., & LaBorde, C.T. (2009). *Parent action: Acceptance and commitment training for parents* [Conference presentation]. Association for Behavior Analysis Annual Convention 2009, Phoenix, AZ, United States.

National Institute for Health and Care Excellence. (2021). *Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain.(*NICE guideline NG193) Https://www.nice.org.uk/guidance/NG1193

Neece, C. L., & Lima, E. J. (2016). Interventions for Parents of People with Intellectual Disabilities. *Current Developmental Disorders Reports*, *3*(2), 124-128. https://doi.org/10.1007/s40474-016-0088-4

Newcomb, M. E., & Mustanski, B. (2014). Diaries for observation or intervention of health behaviors: factors that predict reactivity in a sexual diary study of men who have sex with men. *Annals of Behavioral Medicine*, *47*(3), 325-334. https://doi.org/10.1007/s12160-013-9549-8

O'Connor, M., Farrell, L., Munnelly, A., & McHugh, L. (2017). Citation analysis of relational frame theory: 2009–2016. *Journal of Contextual Behavioral Science*, *6*(2), 152-158. https://doi.org/10.1016/j.jcbs.2017.04.009

O'Brien, K. M. (2011). *Evaluating the effectiveness of a parent training protocol based on an acceptance and commitment therapy philosophy of parenting* [Doctoral dissertation, University of North Texas]. ProQuest Dissertations and Theses Global. https://www.proquest.com/pqdtglobal/docview/1012296227/B324117CDDFB4A50PQ/1?accountid=10766&sourcetype=Dissertations%20&%20Theses

O'Neill, L., Latchford, G., McCracken, L. M., & Graham, C. D. (2019). The development of the Acceptance and Commitment Therapy Fidelity Measure (ACT-FM): A delphi study and field test. *Journal of Contextual Behavioral Science*, *14*, 111-118. https://doi.org/10.1016/j.jcbs.2019.08.008

Ong, C. W., Lee, E. B., Krafft, J., Terry, C. L., Barrett, T. S., Levin, M. E., & Twohig, M. P. (2019). A randomized controlled trial of acceptance and commitment therapy for clinical perfectionism. *Journal of Obsessive-Compulsive and Related Disorders*, *22*, 100444. https://doi.org/10.1016/j.jocrd.2019.100444

Öst, L. G. (2008). Efficacy of the third wave of behavioral therapies: A systematic review and meta-analysis. *Behaviour research and therapy*, *46*(3), 296-321. https://doi.org/10.1016/j.brat.2007.12.005

Oulton, K., & Heyman, B. (2009). Devoted protection: How parents of children with severe learning disabilities manage risks. *Health, risk & society, 11*(4), 303-319. https://doi.org/10.1080/13698570903013631

Ouyang, L., Grosse, S. D., Riley, C., Bolen, J., Bishop, E., Raspa, M., & Bailey Jr, D. B. (2014). A comparison of family financial and employment impacts of fragile X syndrome, autism spectrum disorders, and intellectual disability. *Research in Developmental Disabilities,* 35(7), 1518-1527. https://doi.org/10.1016/j.ridd.2014.04.009

Papadopoulos, C., Lodder, A., Constantinou, G., & Randhawa, G. (2019). Systematic Review of the Relationship Between Autism Stigma and Informal Caregiver Mental Health. *Journal of Autism and Developmental Disorders*, *49*(4), 1665-1685. https://doi.org/10.1007%2Fs10803-018-3835-z

Park, G. A., & Lee, O. N. (2022). The Moderating Effect of Social Support on Parental Stress and Depression in Mothers of Children with Disabilities. *Occupational therapy international*, *2022*, 5162954. https://doi.org/10.1155/2022/5162954

Parkin, E., Kennedy, S., Bate, A., Long, R., Hubble, S., & Powell, A. (2018). Learning Disability-overview of policy and services. *Learning*, *4*(07058), 1-32. https://core.ac.uk/reader/199233310

Patel, M. X., Doku, V., & Tennakoon, L. (2003). Challenges in recruitment of research participants. *Advances in Psychiatric Treatment*, *9*(3), 229-238. https://doi.org/10.1192/apt.9.3.229

Pawel, S., Heyard, R., Micheloud, C., & Held, L. (2024). Replication of null results: Absence of evidence or evidence of absence?. *eLife*, *12*, RP92311. https://doi.org/10.7554/elife.92311

Pickard, L. (2001). Carer break or carer-blind? Policies for informal carers in the UK. *Social Policy & Administration*, *35*(4), 441-458. https://doi.org/10.1111/1467-9515.00244

Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *The Journals of gerontology. Series B, Psychological Sciences and Social Sciences*, *62*(2), 126-37. https://doi.org/10.1093/geronb/62.2.P126

Plumb, J. C., & Vilardaga, R. (2010). Assessing treatment integrity in acceptance and commitment therapy: Strategies and suggestions. *International Journal of Behavioral Consultation and Therapy*, *6*(3), 263. https://doi.org/10.1037/h0100912

Poddar, S., Sinha, V. K., & Urbi, M. (2015). Acceptance and commitment therapy on parents of children and adolescents with autism spectrum disorders. *International Journal of Educational and Psychological Researches*, *1*(3), 221. https://doi.org/10.4103/2395-2296.158331

Polanin, J. R., Tanner-Smith, E. E., & Hennessy, E. A. (2016). Estimating the difference between published and unpublished effect sizes: A meta-review. *Review of Educational Research*, *86*(1), 207-236. https://doi.org/10.3102/0034654315582067

Postorino, V., Fatta, L. M., Sanges, V., Giovagnoli, G., De Peppo, L., Vicari, S., & Mazzone, L. (2016). Intellectual disability in Autism Spectrum Disorder: Investigation of prevalence in an Italian sample of children and adolescents. *Research in developmental disabilities*, *48*, 193-201. https://doi.org/10.1016/j.ridd.2015.10.020

Power, A. (2009). ‘It's the system working for the system’: carers’ experiences of learning disability services in Ireland. *Health & social care in the community*, *17*(1), 92-98. https://doi.org/10.1111/j.1365-2524.2008.00807.x

Powers, M. B., Vörding, M. B. Z. V. S., & Emmelkamp, P. M. (2009). Acceptance and commitment therapy: A meta-analytic review. *Psychotherapy and psychosomatics*, *78*(2), 73-80. https://doi.org/10.1159/000190790

Ragni, B., Boldrini, F., Mangialavori, S., Cacioppo, M., Capurso, M., & De Stasio, S. (2022). The Efficacy of Parent Training Interventions with Parents of Children with Developmental Disabilities. *International Journal of Environmental Research and Public Health*, *19*(15), 9685. https://doi.org/10.3390%2Fijerph19159685

Rajan, A. M., & Romate, J. (2022). Resilience and Coping by Parents of Children with Intellectual Disability in Kerala, South India. *Disability, CBR & Inclusive Development*, *33*(3), 25-40. https://www.doi.org/10.47985/dcidj.524

Rauwenhoff, J., Peeters, F., Bol, Y., & Van Heugten, C. (2019). The BrainACT study: acceptance and commitment therapy for depressive and anxiety symptoms following acquired brain injury: study protocol for a randomized controlled trial. *Trials*, *20*(1), 1-10. https://doi.org/10.1186/s13063-019-3952-9

Rayan, A., & Ahmad, M. (2018). The psychometric properties of the mindful attention awareness scale among Arab parents of children with autism spectrum disorder. *Archives of Psychiatric Nursing*, *32*(3), 444-448. https://doi.org/10.1016/j.apnu.2018.01.001

Reid, C., Gill, F., Gore, N., & Brady, S. (2016). New ways of seeing and being: Evaluating an acceptance and mindfulness group for parents of young people with intellectual disabilities who display challenging behaviour. *Journal of Intellectual Disabilities*, *20*(1), 5-17. https://doi.org/10.1177/1744629515584868

Riendeau, R. P., Sullivan, J. L., Meterko, M., Stolzmann, K., Williamson, A. K., Miller, C. J., Kim, B., & Bauer, M. S. (2018). Factor structure of the Q-LES-Q short form in an enrolled mental health clinic population. *Quality of Life Research: an International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *27*(11), 2953-2964. https://doi.org/10.1007/s11136-018-1963-8

Roberts, C., Mazzucchelli, T., Studman, L., & Sanders, M. R. (2006). Behavioral family intervention for children with developmental disabilities and behavioral problems. *Journal of Clinical Child & Adolescent Psychology*, *35*(2), 180-193. https://doi.org/10.1207/s15374424jccp3502_2

Robinson, A., De Boos, D., & Moghaddam, N. (2023). Acceptance and commitment therapy (ACT) for people with dementia experiencing psychological distress: A hermeneutic single-case efficacy design (HSCED) series. *Counselling and Psychotherapy Research*, *23*(4), 1108–1122. https://doi.org/10.1002/capr.12646

Roloff, J., & Zyphur, M. J. (2019). Null Findings, Replications and Preregistered Studies in Business Ethics Research. *Journal of Business Ethics*, *160*(3), 609-619. https://doi.org/10.1007/s10551-018-3864

Ronk, F. R., Korman, J. R., Hooke, G. R., & Page, A. C. (2013). Assessing clinical significance of treatment outcomes using the DASS-21. *Psychological assessment*, *25*(4), 1103. https://doi.org/10.1037/a0033100

Rose, M., Graham, C. D., O'Connell, N., Vari, C., Edwards, V., Taylor, E., McCracken, L., Radunovic, A., Rakowicz, W., Norton, S., & Chalder, T. (2023). A randomised controlled trial of acceptance and commitment therapy for improving quality of life in people with muscle diseases. *Psychological medicine*, *53*(8), 3511-3524. https://doi.org/10.1017/S0033291722000083

Ruiz, F. J. (2010). A review of Acceptance and Commitment Therapy (ACT) empirical evidence: Correlational, experimental psychopathology, component and outcome studies. *International Journal of Psychology and Psychological Therapy*, *10*(1), 125-162. https://contextualscience.org/system/files/Ruiz2010.pdf

Ruiz, F. J., Suárez-Falcón, J. C., & Riaño-Hernández, D. (2016). Psychometric properties of the mindful attention awareness scale in Colombian undergraduates. *Suma psicológica*, *23*(1), 18-24. https://doi.org/10.1016/j.sumpsi.2016.02.003

Saeedifard T., Nazari A. M., Mohsenzadeh F. (2016) Effect of acceptance and commitment therapy on the resiliency of mothers of children with learning disability. *Journal of Research & Health*, 6(2), 263-271. http://jrh.gmu.ac.ir/article-1-1008-en.html

Salimi, M., Mahdavi, A., Yeghaneh, S. S., Abedin, M., & Hajhosseini, M. (2019). The Effectiveness of Group Based Acceptance and Commitment Therapy (ACT) on Emotion Cognitive Regulation Strategies in Mothers of Children with Autism Spectrum. *Maedica*, *14*(3), 240–246. https://doi.org/10.26574/maedica.2019.14.3.240

Sanetti, L. M. H., & Collier-Meek, M. A. (2014). Increasing the rigor of procedural fidelity assessment: an empirical comparison of direct observation and permanent product review methods. *Journal of Behavioral Education*, *23*(1), 60-89. https://doi.org/10.1007/s10864-013-9179-z

Sanetti, L. M., Cook, B. G., & Cook, L. (2021). Treatment fidelity: What it is and why it matters. *Learning Disabilities Research & Practice*, *36*(1), 5-11. https://doi.org/10.1111/ldrp.12238

Sartore, G. M., Pourliakas, A., & Lagioia, V. (2021). Peer support interventions for parents and carers of children with complex needs. *The Cochrane database of systematic reviews*, *12*(12), CD010618. https://doi.org/10.1002/14651858.cd010618.pub2

Saunders, B. S., Tilford, J. M., Fussell, J. J., Schulz, E. G., Casey, P. H., & Kuo, D. Z. (2015). Financial and employment impact of intellectual disability on families of children with autism. *Families, Systems, & Health*, *33*(1), 36. https://doi.org/10.1037/fsh0000102

Seewooruttun, L., & Scior, K. (2014). Interventions aimed at increasing knowledge and improving attitudes towards people with intellectual disabilities among lay people. *Research in developmental disabilities*, *35*(12), 3482-3495. https://doi.org/10.1016/j.ridd.2014.07.028

Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation*, *43*(5), 354-359. https://doi.org/10.1352/0047-6765(2005)43[354:lcsoso]2.0.co;2

Serdar, C. C., Cihan, M., Yücel, D., & Serdar, M. A. (2021). Sample size, power and effect size revisited: simplified and practical approaches in pre-clinical, clinical and laboratory studies. *Biochemia medica*, *31*(1), 27-53. https://doi.org/10.11613/BM.2021.010502

Shahtahmasebi, S., Emerson, E., Berridge, D., & Lancaster, G. (2011). Child disability and the dynamics of family poverty, hardship and financial strain: evidence from the UK.

Journal of Social Policy, *40*(4), 653-673. https://doi.org/10.1017/S0047279410000905

Shearn, J., & Todd, S. (1997). Parental work: an account of the day-to-day activities of parents of adults with learning disabilities. *Journal of Intellectual Disability Research*, *41*(4), 285-301. https://doi.org/10.1111/j.1365-2788.1997.tb00712.x

Silva, H. A. D., Passos, M. H. P. D., Oliveira, V. M. A. D., Palmeira, A. C., Pitangui, A. C. R., & Araújo, R. C. (2016). Short version of the Depression Anxiety Stress Scale-21: is it valid for Brazilian adolescents?. *Einstein (São Paulo)*, *14*, 486-493. http://dx.doi.org/10.1590/s1679-45082016ao3732

Simpson, W. (2021). *Siblings of people with intellectual disability: Relationships and decision-making across the lifespan* [Doctoral Dissertation, Edith Cowan University]. Edith Cowan University Repository. https://ro.ecu.edu.au/theses/2417

Singer, G. H., Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental retardation and developmental disabilities research reviews*, *13*(4), 357-369. https://doi.org/10.1002/mrdd.20175

Singh, N. N., Lancioni, G. E., Winton, A. S., Karazsia, B. T., Myers, R. E., Latham, L. L., & Singh, J. (2014). Mindfulness-based positive behavior support (MBPBS) for mothers of adolescents with autism spectrum disorder: Effects on adolescents' behavior and parental stress. *Mindfulness*, *5*(6), 646-657. https://doi.org/10.1007/s12671-014-0321-3

Smith, A. J. (2017). *Acceptance and commitment therapy for depression and anxiety: an interpretative phenomenological analysis of clients' experiences in a group context* [Doctoral dissertation, London Metropolitan University]. London Metropolitan University Repository. https://repository.londonmet.ac.uk/1221/

Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology*, *29*(1), 113-132. https://doi.org/10.1023/A:1005253514140

Song, J., Mailick, M. R., & Greenberg, J. S. (2018). Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma. *Social Science & Medicine*, *217*, 152-158. https://doi.org/10.1016/j.socscimed.2018.09.044

Staunton, E., Kehoe, C., & Sharkey, L. (2023). Families under pressure: Stress and quality of life in parents of children with an intellectual disability. *Irish journal of psychological medicine*, *40*(2), 192-199. https://doi.org/10.1017/ipm.2020.4

Sterne, J. A. C., Hernán, M. A., Reeves, B. C., Savović, J., Berkman, N. D., Viswanathan, M., Henry, D., Altman, D. G., Ansari, M. T., Boutron, I., Carpenter, J. R., Chan, A.-W., Churchill, R., Deeks, J. J., Hróbjartsson, A., Kirkham, J., Jüni, P., Loke, Y. K., Pigott, T. D., . . . Higgins, J. P. T. (2016). ROBINS-I: A tool for assessing risk of bias in non- randomised studies of interventions. *BMJ*, *355*, 4919. https://doi.org/10.1136/bmj.i4919

Sterne, J. A. C., Savović, J., Page, M. J., Elbers, R. G., Blencowe, N. S., Boutron, I., Cates, C. J., Cheng, H.-Y., Corbett, M. S., Eldridge, S. M., Emberson, J. R., Hernán, M. A., Hopewell, S., Hróbjartsson, A., Junqueira, D. R., Jüni, P., Kirkham, J. J., Lasserson, T., Li, T., . . . Higgins, J. P. T. (2019). RoB 2: A revised tool for assessing risk of bias in randomised trials. *BMJ*, *366*, l4898. https://doi.org/10.1136/bmj.l4898

Stevanovic, D. (2011). Quality of Life Enjoyment and Satisfaction Questionnaire–short form for quality of life assessments in clinical practice: a psychometric study. *Journal of Psychiatric and Mental Health Nursing*, *18*(8), 744-750. http://dx.doi.org/10.1111/j.1365-2850.2011.01735.x

Stockton, D., Kellett, S., Berrios, R., Sirois, F., Wilkinson, N., & Miles, G. (2019). Identifying the underlying mechanisms of change during acceptance and commitment therapy (ACT): A systematic review of contemporary mediation studies. *Behavioural and cognitive psychotherapy*, *47*(3), 332-362. https://doi.org/10.1017/S1352465818000553

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental retardation*, *43*(5), 339-350. https://doi.org/10.1352/0047-6765(2005)43[339:socwdr]2.0.co;2

Stoneman, Z., Brody, G. H., Davis, C. H., & Crapps, J. M. (1989). Role relations between children who are mentally retarded and their older siblings: Observations in three in-home contexts. *Research in Developmental Disabilities*, *10*(1), 61-76. https://doi.org/10.1016/0891-4222(89)90029-2

Stynes, G., & McHugh, L. (2023). Brief acceptance and commitment therapy for shame among adults with experience of mental health difficulties using a randomized multiple baseline, single case experimental design (SCED). *Stigma and Health.* Advance online publication. https://doi.org/10.1037/sah0000450

Tan, K. P., Ang, J. K., Koh, E. B. Y., Pang, N. T. P., & Mat Saher, Z. (2023). Relationship of Psychological Flexibility and Mindfulness to Caregiver Burden, and Depressive and Anxiety Symptoms in Caregivers of People with Dementia. *International journal of* *environmental research and public health*, *20*(5), 4232. https://doi.org/10.3390/ijerph20054232

Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive Aspects of Caregiving: Contributions of the REACH Project to the Development of New Measures for Alzheimer's Caregiving. *Research on Aging*, *26*(4), 429–453. https://doi.org/10.1177/0164027504264493

Thompson, R., Kerr, M., Glynn, M., & Linehan, C. (2014). Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives. *Seizure*, *23*(10), 856-863. https://doi.org/10.1016/j.seizure.2014.07.005

Tian, C., Manfei, X. U., Justin, T. U., Hongyue, W. A. N. G., & Xiaohui, N. I. U. (2018). Relationship between Omnibus and Post-hoc Tests: An Investigation of performance of the F test in ANOVA. *Shanghai archives of psychiatry*, *30*(1), 60. https://doi.org/10.11919%2Fj.issn.1002-0829.218014

Totsika, V., Hastings, R. P., Emerson, E., Berridge, D. M., & Lancaster, G. A. (2011). Behavior problems at 5 years of age and maternal mental health in autism and intellectual disability. *Journal of abnormal child psychology*, *39*, 1137-1147. https://doi.org/10.1007/s10802-011-9534-2

Trute, B., Hiebert-Murphy, D., & Levine, K. (2007). Parental appraisal of the family impact of childhood developmental disability: Times of sadness and times of joy. *Journal of Intellectual and Developmental Disability*, *32*(1), 1-9. https://doi.org/10.1080/13668250601146753

Twohig, M. P., Shoenberger, D., & Hayes, S. C. (2007). A preliminary investigation of acceptance and commitment therapy as a treatment for marijuana dependence in adults. *Journal of applied behavior analysis*, *40*(4), 619-632. https://doi.org/10.1901/jaba.2007.619-632

Twohig, M. P. (2012). Acceptance and commitment therapy: Introduction. *Cognitive and Behavioral Practice*, *19*(4), 499-507. https://doi.org/10.1016/j.cbpra.2012.04.003

UK Government (2014) *Care act*. https://www.legislation.gov.uk/ukpga/2014/23/section/10/enacted

Villatte, J. L., Vilardaga, R., Villatte, M., JC, P. V., Atkins, D. C., & Hayes, S. C. (2015). Acceptance and Commitment Therapy modules: Differential impact on treatment processes and outcomes. *Behaviour Research and Therapy*, *77*, 52-61. https://doi.org/10.1016/j.brat.2015.12.001

Viswanathan, M., Patnode, C. D., Berkman, N. D., Bass, E. B., Chang, S., Hartling, L., Murad, M., Treadwell, R., & Kane, R. L. (2018). Recommendations for assessing the risk of bias in systematic reviews of health-care interventions. *Journal of clinical epidemiology*, *97*, 26-34. https://doi.org/10.1016/j.jclinepi.2017.12.004

Walden, S., Pistrang, N., & Joyce, T. (2000). Parents of adults with intellectual disabilities: Quality of life and experiences of caring. *Journal of Applied Research in Intellectual Disabilities*, *13*(2), 62-76. https://doi.org/10.1046/j.1468-3148.2000.00002.x

Wardley, M. N., Flaxman, P. E., Willig, C., & Gillanders, D. (2016). 'Feel the Feeling': Psychological practitioners' experience of acceptance and commitment therapy well-being training in the workplace. *Journal of health psychology*, *21*(8), 1536-1547. https://doi.org/10.1177/1359105314557977

Warnock, R. (2023) Relational legacies and relative experiences: Austerity, inequality and access to special educational needs and disability (SEND) support in London, England. *The Geographical Journal*, *189*, 1–12. https://doi.org/10.1111/geoj.12536

Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, *6*(1), 115-130. https://doi.org/10.1177/1362361302006001009

Wicksell, R. K., Kemani, M., Jensen, K., Kosek, E., Kadetoff, D., Sorjonen, K., Ingvar, M., & Olsson, G. L. (2013). Acceptance and commitment therapy for fibromyalgia: a randomized controlled trial. *European journal of pain*, *17*(4), 599-611. https://doi.org/10.1002/j.1532-2149.2012.00224.x

Willig, C. (2013). *Introducing qualitative research in psychology* (3rd ed.). Open University Press.

Willner, P., Rose, J., Stenfert Kroese, B., Murphy, G. H., Langdon, P. E., Clifford, C., Hutchings, H., Watkins, A., Hiles, S., & Cooper, V. (2020). Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *33*(6), 1523-1533. https://doi.org/10.1111/jar.12811

Wilson, A. N., Dzugan, E., & Hutchinson, V. D. (2022). Using a nonconcurrent multiple-baseline across-participants design to examine the effects of individualized ACT at school. *Behavior Analysis in Practice*, *15*(1), 141-154. https://doi.org/10.1007/s40617-021-00558-8

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*(2), 203–214. https://doi.org/10. 1901/jaba.1978.11-203

World Health Organisation (2019) International Statistical Classification of Diseases and Related Health Problems. (11th ed.). https://icd.who.int/

Wyrwich, K., Harnam, N., Revicki, D. A., Locklear, J. C., Svedsäter, H., & Endicott, J. (2009). Assessing health-related quality of life in generalized anxiety disorder using the Quality Of Life Enjoyment and Satisfaction Questionnaire. *International Clinical Psychopharmacology*, *24*(6), 289-295. https://doi.org/10.1097/YIC.0b013e32832d6bf4

Yannamani, N., Zia, A., & Khalil, N. (2009). Family carers of people with learning disabilities: common themes across caring. *Psychiatry*, *8*(11), 441-444. https://doi.org/10.1016/j.mppsy.2009.07.007

Yavuz, F., Ulusoy, S., Iskin, M., Esen, F. B., Burhan, H. S., Karadere, M. E., & Yavuz, N. (2016). Turkish version of Acceptance and Action Questionnaire-II (AAQ-II): A reliability and validity analysis in clinical and non-clinical samples. *Klinik Psikofarmakoloji Bülteni-Bulletin of Clinical Psychopharmacology*, *26*(4), 397-408. https://doi.org/10.5455/bcp.20160223124107

Yoong, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research, 56*(6), 609-619. https://doi.org/10.1111/j.1365-2788.2011.01501.x

Zody, M. C. (2017). *Acceptance and Commitment Therapy (ACT) as a one-day workshop for parents of children with an Autism Spectrum Disorder* [Doctoral dissertation, The Wright Institute]. ProQuest Dissertations and Theses Global. https://www.proquest.com/docview/1901512248?pq-origsite=gscholar&fromopenview=true&sourcetype=Dissertations%20&%20Theses

Appendix A

Characteristics of the Studies Included

Author, Year and Country	**Study Design**	**Number, gender and mean age of participants, (years) and drop outs**	**Description Intervention and Control Groups**	**Number of Core ACT Processes and Measures of Treatment Fidelity and Social Validity**	**Main Findings**
Blackledge and Hayes, 2006; USA	Single group pretest-posttest design	20 parents of children diagnosed with autism (15 mothers and 5 fathers); Mean age: 42.9 years; 3 dropped out.	IG: 2-day ACT group (14 hours). Facilitated by a Clinical Psychologist (the primary author).	All six ACT processes. Measures of treatment fidelity used (video tapes with an inter-rater reliability of 0.93) No measures of social validity used.	From 3 weeks pre-group to 3 months follow up: Significant improvements in depression (*p* = 0.06), general psychiatric problems (*p* = 0.048), psychological distress (*p* = 0.021), cognitive fusion (*p* = 0.035), and experiential avoidance (*p* = 0.043).
Corti et al., 2018; Italy	Non-randomised pretest-posttest with control group design	42 parents of children diagnosed with autism in the last 6 months (20 fathers and 22 mothers). CG mean age: 37.86; IG mean age: 39.65. 1 dropped out.	IG: 12 ACT sessions lasting 1.5 hours per session, every two weeks (*n* = 21). Facilitator: Two CBT therapists with expertise in ACT. CG: No direct intervention (*n* = 22) Both groups: BPT for 20 hours per week for 6 months.	All six ACT processes No measures of social validity or treatment fidelity.	At post-test, significant improvements in mindfulness (*p*<0.02, ηp2 = 0.14) compared to CG. No significant difference in stress (*p* = 0.06, ηp2 = 0.09), and cognitive fusion (*p* = 0.74, ηp2 = 0.14) between groups. IG: Positive reports of subjective evaluations of treatment and change.

Author, Year and Country	**Study Design**	**Number, gender and mean age of participants, (years) and drop outs**	**Description Intervention and Control Groups**	**Number of Core ACT Processes and Measures of Treatment Fidelity and Social Validity**	**Main Findings**
Fung et al., 2018; Canada	Single group pretest-posttest design	33 mothers of children diagnosed with ASD (mean age: 44.8 years); 4 mothers did not complete all outcome measures.	Facilitators: Two mothers of children with ASD, trained in ACT. IG: 1.5 day session and a refresher evening session (1 month later).	All six ACT processes. No measures of treatment fidelity or social validity.	Pre- to post-intervention: Significant improvements in valued-living (*p* < 0.001), psychological flexibility (*p* = 0.001), and cognitive fusion (*p* = 0.01); these significant improvements were maintained at the 3 month follow-up.
Hahs, et al., 2019; USA	RCT	18 parents of children with ASD (5 fathers and 13 mothers); Mean age: 45.5 years; No dropouts.	Parents were matched on depression and experiential avoidance scores and randomly allocated to groups using computer software. IG: Facilitated by a the primary author (professional role not stated) 2 ACT sessions (4 hours in total, one week apart) + weekly BPT. CG: Weekly BPT.	All six ACT processes. No measures of treatment fidelity or social validity.	At one week post-intervention, significant improvements in experiential avoidance (*p* = 0.0318, *d*= 0.94), depression (*p* = 0.0239, *d*= −1.01), cognitive fusion (*p* = 0.0485, *d*= 0.83), awareness states (*p* = 0.007, *d*= 1.29), shame (*p* = 0.0052, *d*= −1.37), and values (*p* = 0.0159, *d*= 1.11), compared to CG. No significant improvements differences in thought suppression (*p* = 0.1732) and mindfulness (*p* = 0.2506) between groups.

Author, Year and Country	**Study Design**	**Number, gender and mean age of participants, (years) and drop outs**	**Description Intervention and Control Groups**	**Number of Core ACT Processes and Measures of Treatment Fidelity and Social Validity**	**Main Findings**
Joekar et al., 2016; Iran	Non-randomised pretest-posttest with control group design	24 mothers of children with high functioning autism. IG parents' mean age: 33.58 years CG parents' mean age: 36.33 years No dropouts.	IG: 8 ACT group sessions (session duration not reported). CG: Weekly individual counselling sessions. Mothers were not randomly allocated to groups. No information on facilitators.	All six ACT processes. No measures of treatment fidelity or social validity.	At post-intervention: significant improvements in experiential avoidance (*p* = 0.001) and depression (*p* = 0.01), compared to CG. No significant differences in anxiety (*p* = 0.069), stress (*p* = 0.365), and quality of life between groups (*p* = 0.071).
Jogdand and Magar, 2020; India	Single group pretest-posttest design	30 parents of children with ASD. Average range 25-30 years (the number of mothers and fathers was not reported). No dropouts.	IG: ACT group (no information on the duration and frequency of sessions). No information on the facilitator(s).	No information on the ACT processes used. No measures of treatment fidelity or social validity.	Pre- to post-intervention: Significant improvements in depression (*p* = 0.01), stress (*p* = 0.01), and anxiety (*p* = 0.01).

Author, Year and Country	**Study Design**	**Number, gender and mean age of participants, (years) and drop outs**	**Description Intervention and Control Groups**	**Number of Core ACT Processes and Measures of Treatment Fidelity and Social Validity**	**Main Findings**
Lobato et al., 2022 Spain	Single group pretest-posttest design	36 family members of children diagnosed with IDs (the types of family member were not specified). Mean age: 55.8 years 4 dropped out.	IG: Three ACT group sessions lasting 3 hours (9 hours in total) delivered by the author (psychologist trained in ACT).	All six ACT processes. No measures of treatment fidelity or social validity.	From pre-intervention to two months follow-up, significant improvements in psychological flexibility (*p* = <0.001; *d*= 1.19), perceived stress (*p* = <0.001; *d*= 0.66), psychological distress (*p*<0.001; *d*= 1.08), and thought suppression (*p*<0.001; *d*= 1.19). From one week pre-and post-intervention: significant increases in positive familial interactions (*p*<0.001; *d*= 1.384), and decreases in negative familial interactions (*p*<0.001; *d*= -1.422).
Lunsky et al., 2017; Canada	Single group pretest-posttest design	33 mothers of children and adolescents diagnosed with ASD. 4 mothers did not complete all of the outcome measures.	Facilitators: 2 mothers and one father (clinician and primary author), all trained to facilitate ACT exercises. IG: 1 evening session, 1 full-day session and a refresher evening session (1 month later).	All six ACT processes. No measures of treatment fidelity or social validity used.	From pre to post-intervention, significant improvements in physical health (*p* = 0.004), depressive symptoms (*p* < 0.05), and stress (*p* = 0.001); these significant improvements were maintained at 2 month follow-up.

Author, Year and Country	**Study Design**	**Number, gender and mean age of participants, (years) and drop outs**	**Description Intervention and Control Groups**	**Number of Core ACT Processes and Measures of Treatment Fidelity and Social Validity**	**Main Findings**
Marino et al., 2021; Italy	Single Blind RCT Group membership was blinded to data collectors, outcome assessors and primary researchers.	20 pairs of parents of children with ASD (*n* = 40) IG mean age: 40.6 years CG mean age: 42.0 years. Parents' gender was not reported.	Parents were matched on clinical and demographic information and randomly allocated to groups. IG: ACT Matrix protocol (*n* = 20) CG: BPT (*n* = 20). Both groups lasted six months (90 minute sessions over 24 weeks) Facilitators were expert therapists (not aware of study aims or clinical information).	All six ACT processes. No measures of treatment fidelity or social validity used.	At post-intervention, significant improvements in psychological flexibility ($p < 0.001$), awareness states ($p < 0.001$), and personal values in everyday life ($p < 0.001$), compared to CG. No significant differences in parental stress and parents' perception of their child's behaviours between groups (p values not reported).
Poddar et al., 2015; India	Single group pretest-posttest design	5 mothers of children and adolescents diagnosed with ASD and ID (mean age: 39.54 years).	IG: 10 ACT sessions (over 2 months) No information on facilitator.	Four ACT processes: acceptance, defusion, values and committed action No measures of social validity and treatment fidelity.	Pre- to post-intervention: Significant improvements in anxiety ($p = 0.04$), depression ($p = 0.04$) psychological flexibility ($p = 0.04$) and psychological QoL ($p = 0.04$). No significant differences in physical ($p =0.52$), social ($p = 0.23$), and environment ($p = 0.34$) QoL domains.

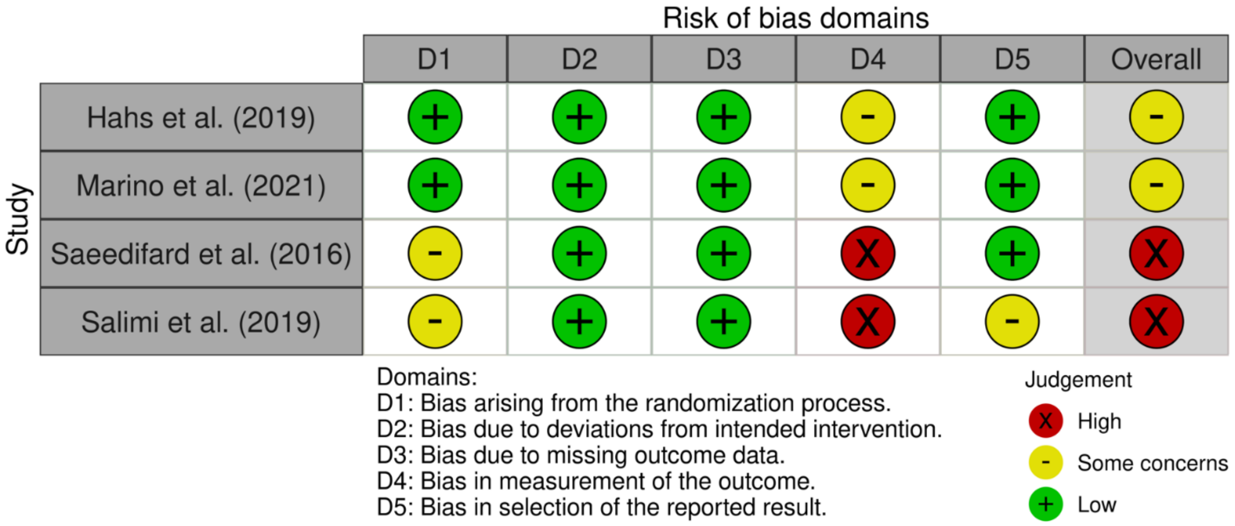
Author, Year and Country	**Study Design**	**Number, gender and mean age of participants, (years) and drop outs**	**Description Intervention and Control Groups**	**Number of Core ACT Processes and Measures of Treatment Fidelity and Social Validity**	**Main Findings**
Saeedifard et al., 2016; Iran	RCT	30 mothers of children with IDs IG mean age: 35.47 years, CG mean age = 36.44 years. No dropouts.	IG: 9 ACT sessions over 9 weeks (n = 15). Duration of sessions not reported. Facilitator: Teacher (primary author) trained in ACT. CG: No intervention (n =15).	All six ACT processes. No measures of treatment fidelity or social validity.	At post-intervention, Significant increases in resiliency (*p* = 0.01; *η2* = 0.74*)*, compared to the CG.
Salimi et al., 2019; Iran	RCT	30 mothers of children with autism (participant age was not reported)	IG: 8 sessions lasting 2 hours each (16 hours in total) (n = 15). No information on the group facilitator. CG = no intervention (n = 15).	Four ACT processes: Acceptance, values and committed actions, and self as context. No measures of treatment fidelity or social validity used.	At post intervention, significant improvements in all six cognitive emotion regulation strategies, compared to the CG (*p*<0.05).

Autism Spectrum Disorder (ASD); Behavioural Parent training (BPT); Control Group (CG); Intervention Group (IG); Randomized Controlled Trial (RCT).

Appendix B

Domain and Overall Risk of Bias of Scores

Risk of Bias Assessment for Randomised Control Trials (RoB 2)



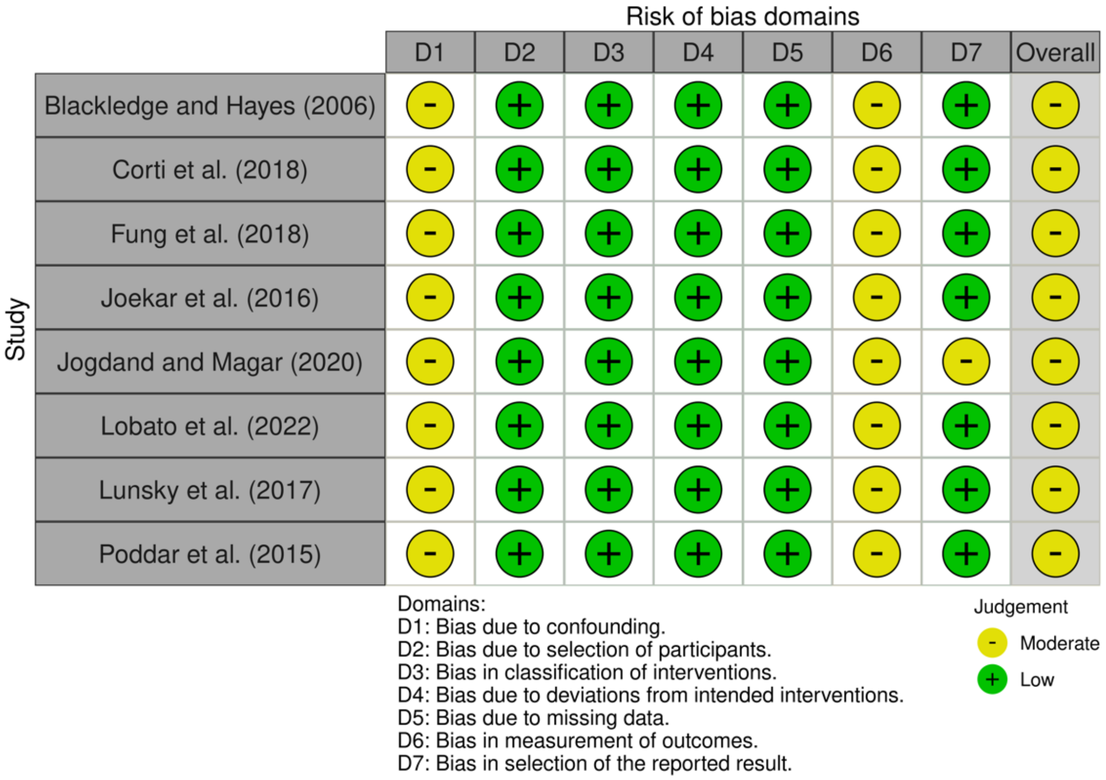
Risk of bias domains

Study	D1	D2	D3	D4	D5	Overall
Hahs et al. (2019)	+	+	+	-	+	-
Marino et al. (2021)	+	+	+	-	+	-
Saeedifard et al. (2016)	-	+	+	X	+	X
Salimi et al. (2019)	-	+	+	X	-	X

Domains:
D1: Bias arising from the randomization process.
D2: Bias due to deviations from intended intervention.
D3: Bias due to missing outcome data.
D4: Bias in measurement of the outcome.
D5: Bias in selection of the reported result.

Judgement
X High
- Some concerns
+ Low

Risk of Bias Assessment for Non-Randomised Studies (ROBIN-I)



Risk of bias domains

Study	D1	D2	D3	D4	D5	D6	D7	Overall
Blackledge and Hayes (2006)	-	+	+	+	+	-	+	-
Corti et al. (2018)	-	+	+	+	+	-	+	-
Fung et al. (2018)	-	+	+	+	+	-	+	-
Joekar et al. (2016)	-	+	+	+	+	-	+	-
Jogdand and Magar (2020)	-	+	+	+	+	-	-	-
Lobato et al. (2022)	-	+	+	+	+	-	+	-
Lunsky et al. (2017)	-	+	+	+	+	-	+	-
Poddar et al. (2015)	-	+	+	+	+	-	+	-

Domains:
D1: Bias due to confounding.
D2: Bias due to selection of participants.
D3: Bias in classification of interventions.
D4: Bias due to deviations from intended interventions.
D5: Bias due to missing data.
D6: Bias in measurement of outcomes.
D7: Bias in selection of the reported result.

Judgement
- Moderate
+ Low

Appendix C

Summary of the ACT Intervention Protocol

The following protocol is based on a combination of exercises and ideas used from the following ACT text books:

- The Happiness Trap (Harris, 2008)
- Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change (Hayes et al., 1999).
- ACT Made Simple: An Easy-To-Read Primer on Acceptance and Commitment Therapy (Harris, 2019)
- Learning ACT: An Acceptance & Commitment Therapy Skills-Training Manual for Therapists (Luoma et al., 2007).

9am – 10.25am (1 hour 25 minutes)	Introduction (15 minutes)
	Carer Burden/Experiences (15 minutes)
	Goals and Assumptions of ACT (5 minutes)
	Acceptance: Creative Hopelessness (20 minutes)
	Internal Struggles Video (5 minutes)
	Expansion Exercise (15 minutes)
	Contact with the Present Moment (10 minutes)
BREAK at 10.25am – 10.40am (15 minutes)	
10.40am – 12.05pm (1 hour 25 minutes)	Missing Out Video and Discussion (10 minutes)
	Dropping an Anchor (10 minutes)
	Walking Meditation (15 minutes)
	Informal Mindfulness Exercises (10 minutes)
	The “hands as thoughts & feelings” exercise (10 minutes)
	Explanation of Fusion and Defusion (15 minutes)
	Leaves on a Stream (15 minutes)
LUNCH 12.05pm – 12.35pm (30 minutes)	
12.35 pm – 2.10pm (1 hour 35 minutes)	Labelling Thoughts as What They Are (15 minutes)
	Defusion Exercises (10 minutes)
	When to use defusion skills (5 minutes)

	Introduction to Self-as-context (15 minutes)
	Sky and Weather Metaphor (5 minutes)
	Observer Self Video (15 minutes)
	Defusion from self-concept (20 minutes)
	Introduction to Values (10 minutes)
BREAK 2.10pm – 2.25pm (15 minutes)	
1 hour 30 minutes (2.25pm – 3.55pm)	Identifying Values Exercise (20 minutes)
	Values-based action (20 minutes)
	Barriers to value-based actions (20 minutes)
	Reflections on the session (15 minutes)
	Ending the session (15 minutes)

Intervention Protocol References:

Harris, R. (2008). *The happiness trap: How to stop struggling and start living*. Shambhala Publications.

Harris, R. (2019). *ACT made simple: An easy-to-read primer on acceptance and commitment therapy.* (2nd ed.). New Harbinger Publications.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change***.** New York**:** Guilford Press.

Luoma, J. B., Hayes, S. C., & Walser, R. D. (2007). *Learning ACT: An acceptance & commitment therapy skills-training manual for therapists*. New Harbinger Publications.

McCracken, L. M., (2012). *Acceptance and Commitment Therapy for Chronic Pain.* https://www.div12.org/wp-content/uploads/2015/06/ACT-for-Chronic-Pain-manual-McCracken.pdf

Appendix D

Feedback from Family Carers on Wednesday 27th April 2022

Three family carers were in attendance. This document summarises the feedback provided by the carers.

Would it be preferable to facilitate the group weekly, all on the same day or two half days?

- This would depend on the needs of the group members.
- They suggested that evenings and/or weekends might work better for certain family carers due to work and/or caring commitments.
- One suggestion was that videos could be sent to participants prior to the group to reduce the amount of time needed to attend face-to-face and/or virtually.
- Carers could be broken up into certain cohorts depending on their needs, availability and role. The group would be more compatible if carers with similar circumstances were placed in the same group.
- It would be helpful to facilitate the group all in the same day or to split the group into two sessions.

How many sessions should we offer? How long should each session be?

- I explained that ACT groups can range from 4 hours to 18 hours, and that there is evidence for both brief and long ACT groups.
- The carers felt that 6 – 8 hours would be feasible for family carers to attend (e.g. 2 sessions lasting 3 hours each).

What would be the most convenient place to hold the group? Online, face-to-face or both?

- Carers felt that this should be determined by the needs of the group.
- They suggested that a mix of both face-to-face and virtual groups might meet the needs of different group members.

What would be the minimum and maximum number of participants in a group?

- I explained to the carers that we were aiming to recruit at least 16 participants for the study.
- They felt that there should be a maximum of 6 – 8 people in each group.
- Nevertheless, the carers felt that the group size should be determined by compatibility and needs. For example, it might be helpful to have a smaller group for dads rather than mix different family roles.

How long should we allow for informal discussions about family carer's experiences within the group?

- The carers felt that it would be helpful to include time for informal discussions as they felt the group would benefit from this. However, they felt this should be optional for group members as some members may not wish to attend and/or struggle with the unstructured nature of the discussion.
- The length of the discussion might depend on the size of the group (e.g. you could add 30 minutes at the end of a 2 hour group).
- The informal peer support could be framed as a time to spend time with each other at the end of the group to have a cup of tea, process the group and discuss their experiences.

Do you have any feedback on the format and structure of the group?

- Try to organise the group based on compatibility.
- Make sure the group has access to biscuits, tea and coffee to help them feel comfortable and settled into the group.

Do you think this feasible and/or practical for carers to complete all of the outcome measures?

- I explained the outcome measures we are planning to collect as part of this project.
- Carers seemed to think these outcome measures were feasible.
- One suggestion was to complete the baseline outcome measures over the phone with the facilitator (time point 1) during the telephone screening to increase the amount of data collected.

Feedback on inclusion and exclusion criteria? Have I missed anything?

- I explained the inclusion and exclusion criteria for the group.
- Carers commented that some carers might be taking psychotropic medications as this group is more at risk of experiencing distress and/or mental health difficulties.
- One suggestion was to include carers who have remained on the same psychotropic medication (e.g. dosage) for a long amount of time and to assess this on a case by case basis.
- The carers noted that step-parents and/or partners might be in a caring role and therefore we might need to think about the definition of a "family carer" so this includes all family carers.

How can we reach out to other types of family members e.g. siblings?

- The carers stated that the mothers of children and/or adults have typically attended similar groups and other family members (e.g. fathers) often do not attend due to other commitments e.g. work.

- Carers could be broken up into certain cohorts depending on their family role. This might free up family carers to talk about their different experiences and potential challenges
- One carer suggested that it might be helpful to facilitate an all-male carer group. In this case, it might be helpful to consider a male facilitator.
- The carers reported that many siblings do not identify themselves as sibling carers and/or carers, and therefore it would be helpful to include “siblings of adults with learning disabilities” in the study leaflet to maximise recruitment.

Appendix E

Study Leaflet

Free Workshops for Family Carers of Adults with Learning Disabilities

Are you a father, mother, sibling, guardian or relative of an adult with a learning disability?

Do you experience any stress related to caregiving?

Would you like support to develop relaxation and coping skills to manage stress related to caregiving?
Would you like to meet other family carers?

We are running acceptance and commitment training workshops for family carers. The workshops will be used as a study to fulfil the researcher's requirements as part of their doctorate in Clinical Psychology, at the University of Essex

If you would like to participate, please email [Name removed] (Chief Investigator) via email: [Email removed] or [Name removed] (Clinical Psychologist) via email: [Email removed].

Date:
Time:
Location:

University of Essex

NHS
Essex Learning Disability
Partnership

Appendix F

Screening Questions

Adapted from Kowalkowski (2012) for the purpose of this study.

Name:______________________________

Contact Information:__________________________

1. Are you currently the relative and/or guardian of an adult with a diagnosis of Learning Disability (LD)? Yes No
2. Was your relative formally diagnosed with a LD? Yes No
3. Are you proficient in the English language? Yes No
4. Have you previously received Acceptance and Commitment Therapy? Yes No
5. Are you currently receiving any other therapy or psychotropic medication?____________________________
6. Do you have any major physical health issues?_____________________________
7. Do you have any significant mental health difficulties or problems with substance abuse and/or dependence?_______________________________

Availability to attend the group:

Preference (circle)

Online Face-to-face No preference

Appendix G

Social Validity Questionnaire

Adapted from Wilson et al. (2022) and Kowalkowski (2012) and modified for the purpose of this study.

Please answer the following questions as honestly and accurately as possible.

1. How much did you enjoy the ACT activities?

Not at all	Sometimes	Often	A lot
1	2	3	4

2. How much did you learn by doing the ACT activities?

Not at all	Sometimes	Often	A lot
1	2	3	4

3. How much did you learn about thoughts and feelings?

Not at all	Sometimes	Often	A lot
1	2	3	4

4. How often do you plan to use the ideas/skills you learned in the ACT activities?

Not at all	Sometimes	Often	A lot
1	2	3	4

5. Overall how satisfied were you with the ACT group?

Not at all	Somewhat	A good amount	A lot
1	2	3	4

6. What did you **most** like about the ACT group? (Please elaborate in the space below)

7. What did you **least** like about the ACT group? (Please elaborate in the space below)

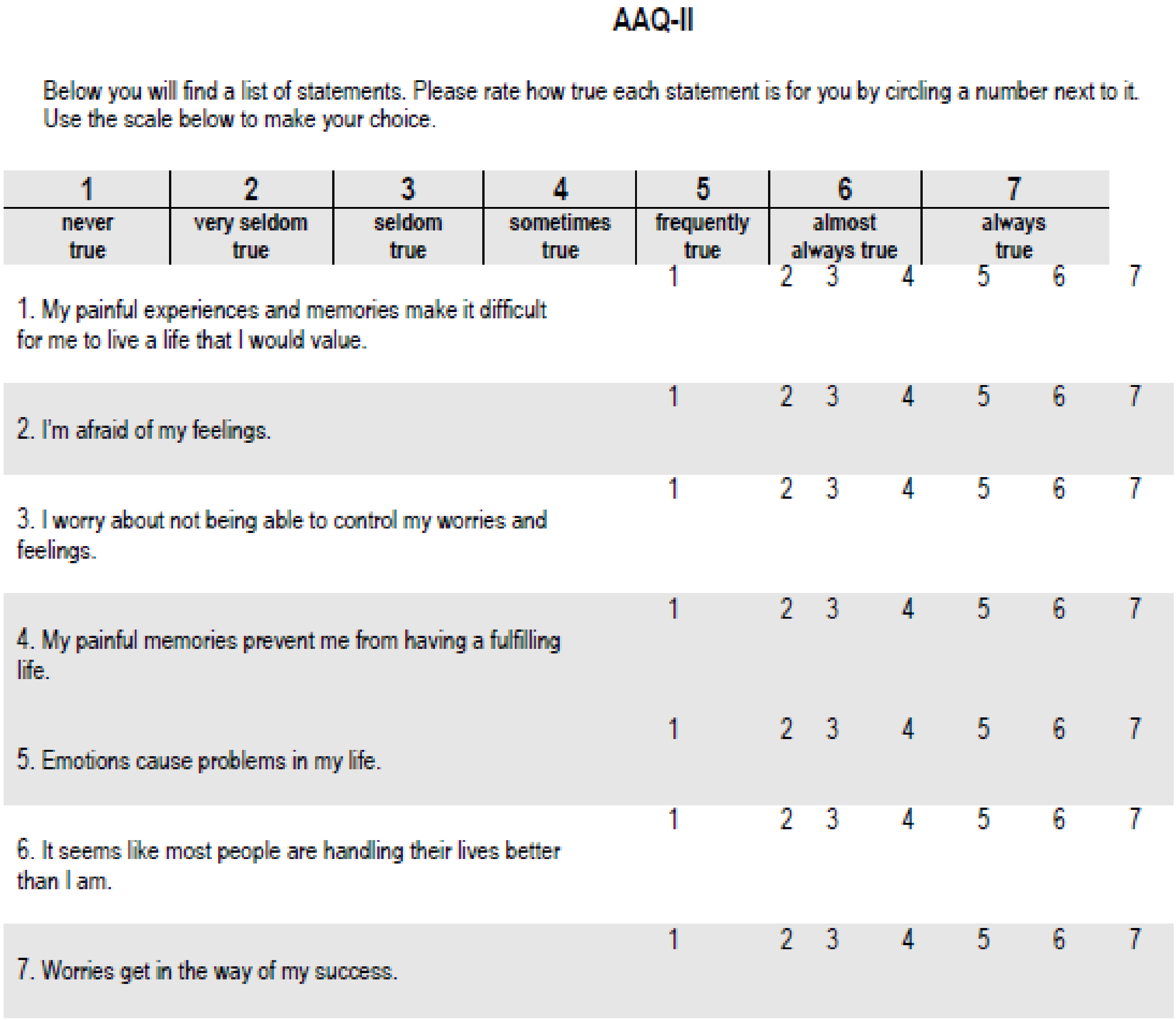
8. What would you do differently or change about the ACT group?

9. Any additional comments or feedback about the group?

Thank you for providing this feedback

Appendix H
ACT Process Measures and Outcome Measures

Acceptance and Action Questionnaire version II



AAQ-II

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

1. My painful experiences and memories make it difficult for me to live a life that I would value.	1	2	3	4	5	6	7
2. I'm afraid of my feelings.	1	2	3	4	5	6	7
3. I worry about not being able to control my worries and feelings.	1	2	3	4	5	6	7
4. My painful memories prevent me from having a fulfilling life.	1	2	3	4	5	6	7
5. Emotions cause problems in my life.	1	2	3	4	5	6	7
6. It seems like most people are handling their lives better than I am.	1	2	3	4	5	6	7
7. Worries get in the way of my success.	1	2	3	4	5	6	7

Cognitive Fusion Questionnaire

CFQ

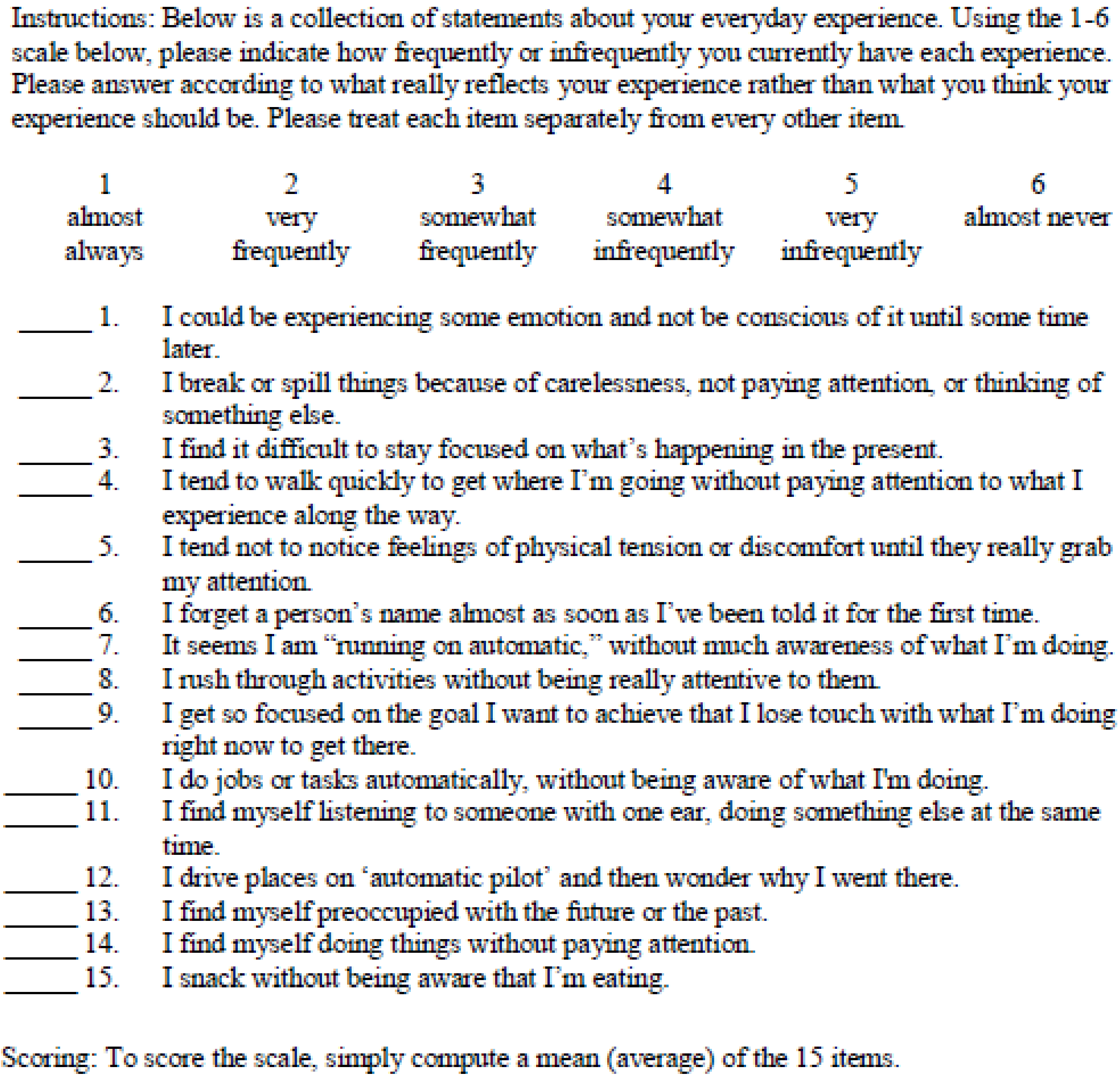
Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

1. My thoughts cause me distress or emotional pain	1	2	3	4	5	6	7
2. I get so caught up in my thoughts that I am unable to do the things that I most want to do	1	2	3	4	5	6	7
3. I over-analyse situations to the point where it's unhelpful to me	1	2	3	4	5	6	7
4. I struggle with my thoughts	1	2	3	4	5	6	7
5. I get upset with myself for having certain thoughts	1	2	3	4	5	6	7
6. I tend to get very entangled in my thoughts	1	2	3	4	5	6	7
7. It's such a struggle to let go of upsetting thoughts even when I know that letting go would be helpful	1	2	3	4	5	6	7

Thank you for completing this questionnaire

The Mindful Attention Awareness Scale (MAAS)



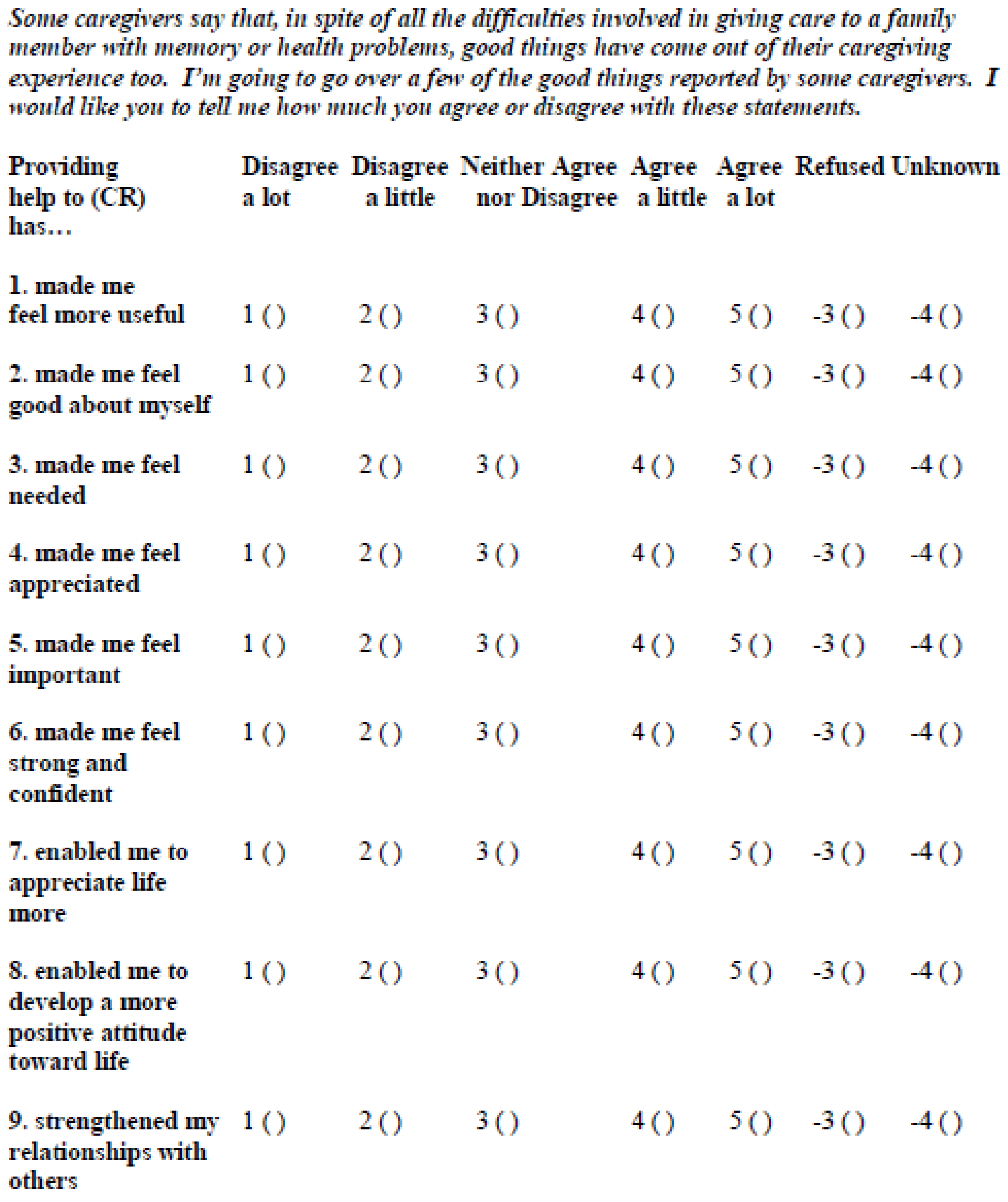
Instructions: Below is a collection of statements about your everyday experience. Using the 1-6 scale below, please indicate how frequently or infrequently you currently have each experience. Please answer according to what really reflects your experience rather than what you think your experience should be. Please treat each item separately from every other item.

1	2	3	4	5	6
almost always	very frequently	somewhat frequently	somewhat infrequently	very infrequently	almost never

_____ 1. I could be experiencing some emotion and not be conscious of it until some time later.
_____ 2. I break or spill things because of carelessness, not paying attention, or thinking of something else.
_____ 3. I find it difficult to stay focused on what's happening in the present.
_____ 4. I tend to walk quickly to get where I'm going without paying attention to what I experience along the way.
_____ 5. I tend not to notice feelings of physical tension or discomfort until they really grab my attention.
_____ 6. I forget a person's name almost as soon as I've been told it for the first time.
_____ 7. It seems I am "running on automatic," without much awareness of what I'm doing.
_____ 8. I rush through activities without being really attentive to them.
_____ 9. I get so focused on the goal I want to achieve that I lose touch with what I'm doing right now to get there.
_____ 10. I do jobs or tasks automatically, without being aware of what I'm doing.
_____ 11. I find myself listening to someone with one ear, doing something else at the same time.
_____ 12. I drive places on 'automatic pilot' and then wonder why I went there.
_____ 13. I find myself preoccupied with the future or the past.
_____ 14. I find myself doing things without paying attention.
_____ 15. I snack without being aware that I'm eating.

Scoring: To score the scale, simply compute a mean (average) of the 15 items.

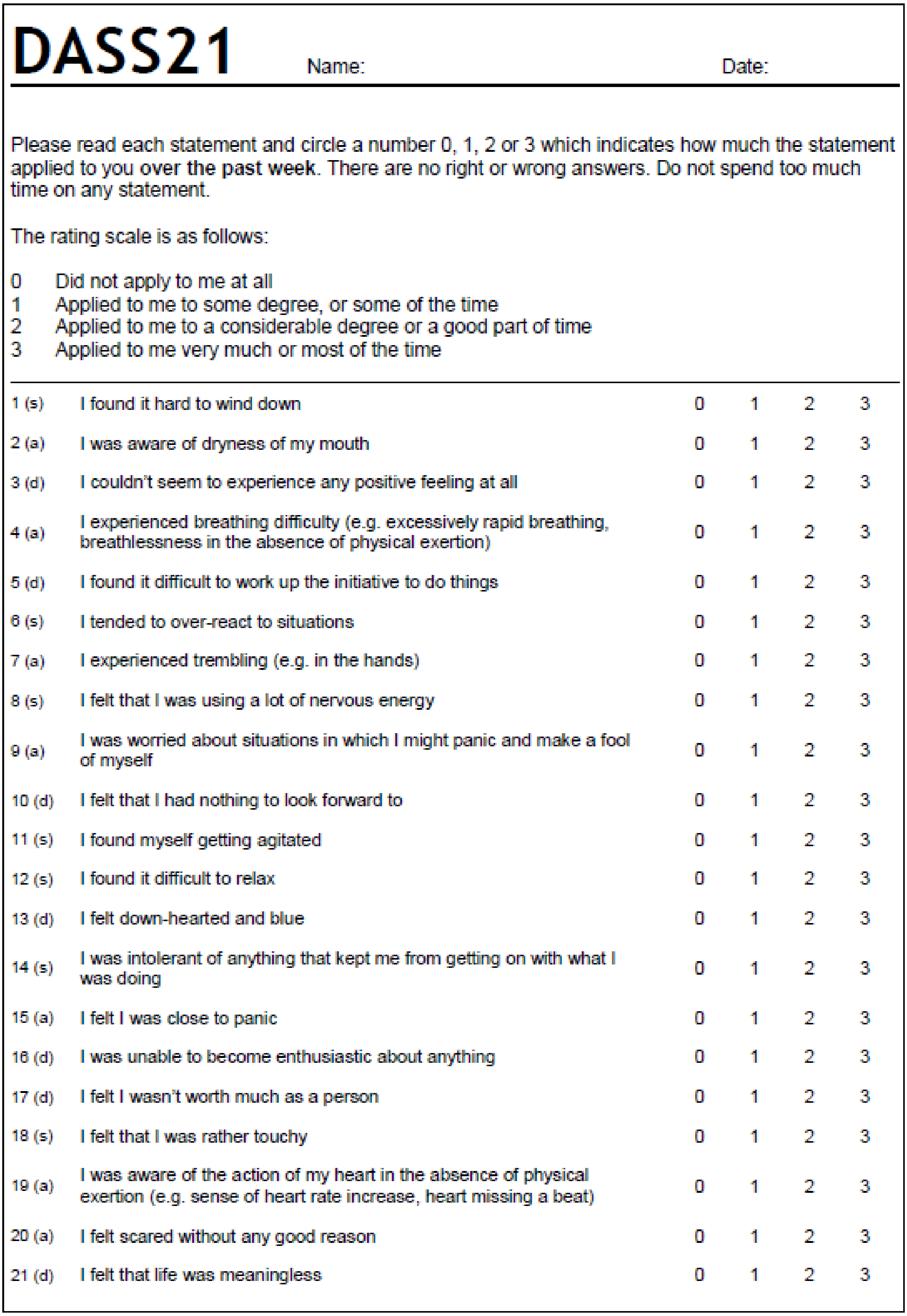
Positive Aspects of Caregiving



Some caregivers say that, in spite of all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. I'm going to go over a few of the good things reported by some caregivers. I would like you to tell me how much you agree or disagree with these statements.

Providing help to (CR) has…	**Disagree a lot**	**Disagree a little**	**Neither Agree nor Disagree**	**Agree a little**	**Agree a lot**	**Refused**	**Unknown**
1. made me feel more useful	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )
2. made me feel good about myself	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )
3. made me feel needed	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )
4. made me feel appreciated	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )
5. made me feel important	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )
6. made me feel strong and confident	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )
7. enabled me to appreciate life more	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )
8. enabled me to develop a more positive attitude toward life	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )
9. strengthened my relationships with others	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )

Depression Anxiety Stress Scales (DASS-21)



DASS21 Name: Date:

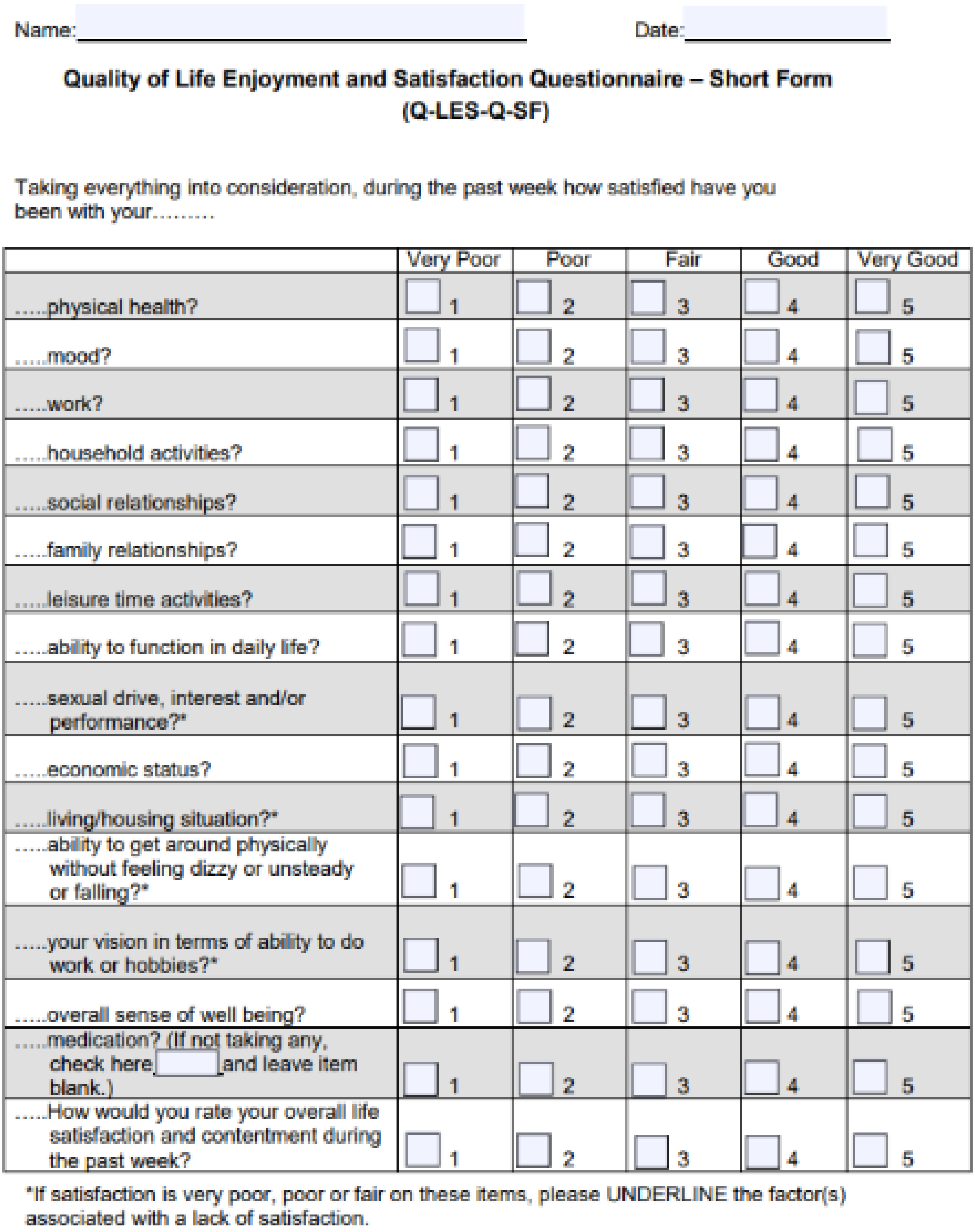
Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree or a good part of time
3 Applied to me very much or most of the time

1 (s)	I found it hard to wind down	0	1	2	3
2 (a)	I was aware of dryness of my mouth	0	1	2	3
3 (d)	I couldn't seem to experience any positive feeling at all	0	1	2	3
4 (a)	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5 (d)	I found it difficult to work up the initiative to do things	0	1	2	3
6 (s)	I tended to over-react to situations	0	1	2	3
7 (a)	I experienced trembling (e.g. in the hands)	0	1	2	3
8 (s)	I felt that I was using a lot of nervous energy	0	1	2	3
9 (a)	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10 (d)	I felt that I had nothing to look forward to	0	1	2	3
11 (s)	I found myself getting agitated	0	1	2	3
12 (s)	I found it difficult to relax	0	1	2	3
13 (d)	I felt down-hearted and blue	0	1	2	3
14 (s)	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15 (a)	I felt I was close to panic	0	1	2	3
16 (d)	I was unable to become enthusiastic about anything	0	1	2	3
17 (d)	I felt I wasn't worth much as a person	0	1	2	3
18 (s)	I felt that I was rather touchy	0	1	2	3
19 (a)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20 (a)	I felt scared without any good reason	0	1	2	3
21 (d)	I felt that life was meaningless	0	1	2	3

Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF)



Name:________________ Date:__________

Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF)

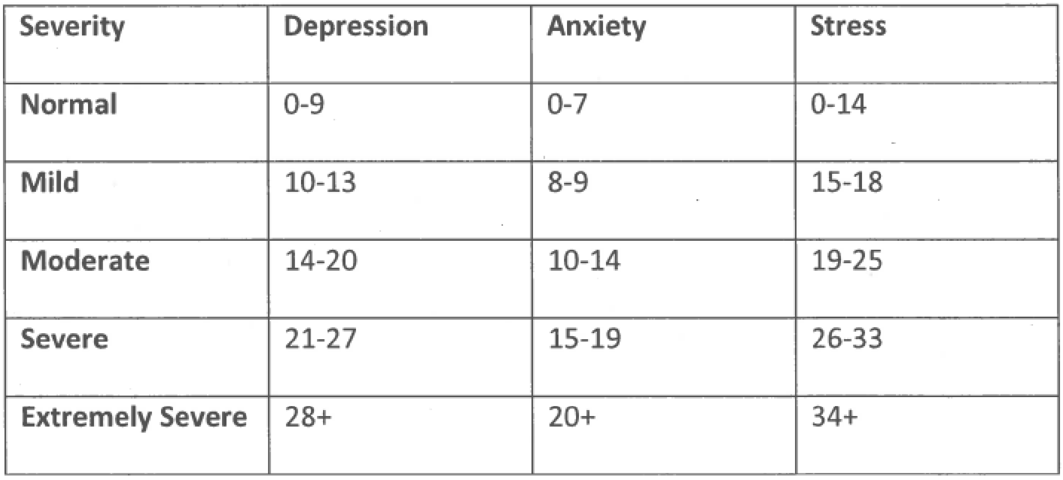
Taking everything into consideration, during the past week how satisfied have you been with your………

	Very Poor	Poor	Fair	Good	Very Good
…..physical health?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..mood?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..work?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..household activities?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..social relationships?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..family relationships?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..leisure time activities?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..ability to function in daily life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..sexual drive, interest and/or performance?*	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..economic status?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..living/housing situation?*	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..ability to get around physically without feeling dizzy or unsteady or falling?*	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..your vision in terms of ability to do work or hobbies?*	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..overall sense of well being?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..medication? (If not taking any, check here ☐ and leave item blank.)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
…..How would you rate your overall life satisfaction and contentment during the past week?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

*If satisfaction is very poor, poor or fair on these items, please UNDERLINE the factor(s) associated with a lack of satisfaction.

Appendix I

DASS-21 Severity Ratings



Severity	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

Appendix J

Worksheet to Record Problematic Behaviours

Participant ID number:

Problematic Behaviour 1:
Problematic Behaviour 2:
Please record the frequency of these behaviours using a tally below:

Week Beginning:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Behaviour 1							
Behaviour 2							

Week Beginning:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Behaviour 1							
Behaviour 2							

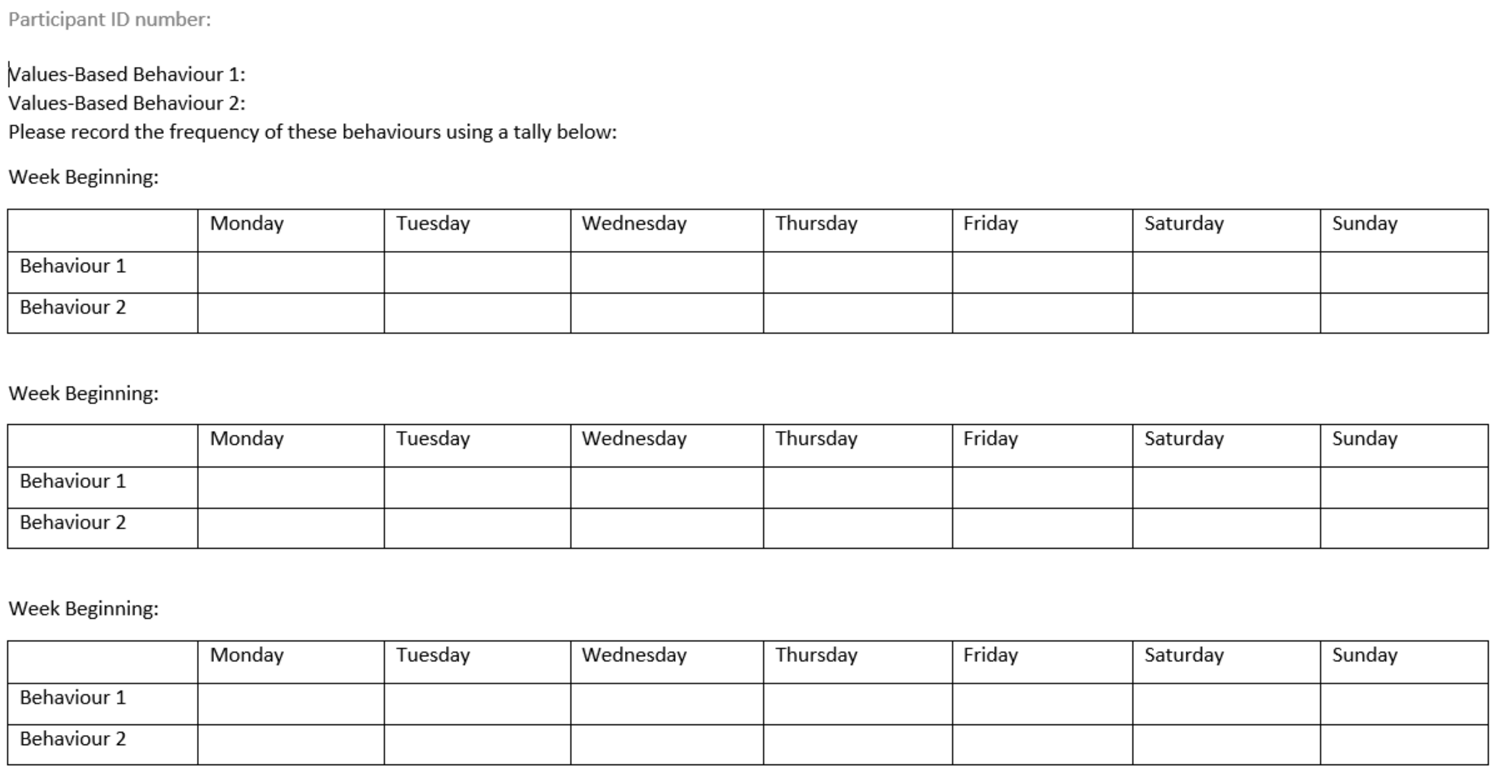
Week Beginning:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Behaviour 1							
Behaviour 2							

Week Beginning:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Behaviour 1							
Behaviour 2							

Worksheet to Record Values-Based Behaviours



Participant ID number:

Values-Based Behaviour 1:
Values-Based Behaviour 2:
Please record the frequency of these behaviours using a tally below:

Week Beginning:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Behaviour 1							
Behaviour 2							

Week Beginning:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Behaviour 1							
Behaviour 2							

Week Beginning:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Behaviour 1							
Behaviour 2							

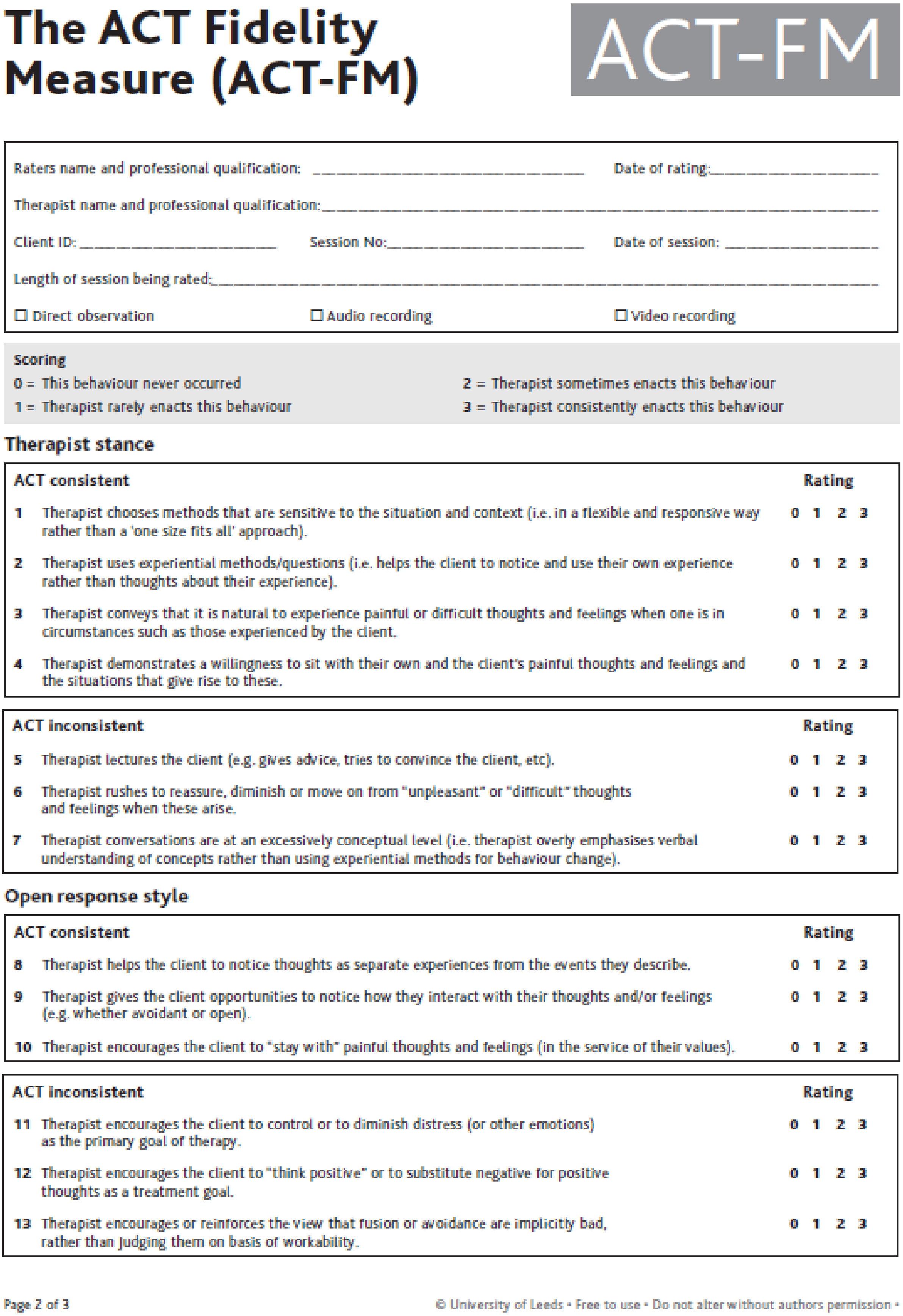
Appendix K

Demographic Questionnaire

Unique participant code:____________________ Age:____________________
Gender:____________________________ Relationship Status:__________________________
Occupation:___________________________ Ethnicity: _______________________________

1. Which of your relatives have been diagnosed with a Learning Disability (LD)?_____________________________
2. Where do they currently live?_________________________
3. What is their age?_______________________
4. Have they received any other diagnoses?____________________________________
5. What support do you currently provide to your relative with a LD? (circle all applicable) Social Emotional Practical Financial
6. How many hours per week do you provide this support?______________________
7. How many years have you been providing this support?_______________________
8. Are you the primary carer for your relative with a LD?_________________________
9. Have you ever received any therapy in relation carer related stress? Yes No
10. If you answered “yes” to the last question, what therapy did you receive? ____________________________________

Appendix L
The ACT Fidelity Measure



The ACT Fidelity Measure (ACT-FM)

ACT-FM

Raters name and professional qualification: ______________________ Date of rating:______________

Therapist name and professional qualification:____

Client ID: ______________ Session No:______________ Date of session: ______________

Length of session being rated:____

☐ Direct observation ☐ Audio recording ☐ Video recording

Scoring

0 = This behaviour never occurred

1 = Therapist rarely enacts this behaviour

2 = Therapist sometimes enacts this behaviour

3 = Therapist consistently enacts this behaviour

Therapist stance

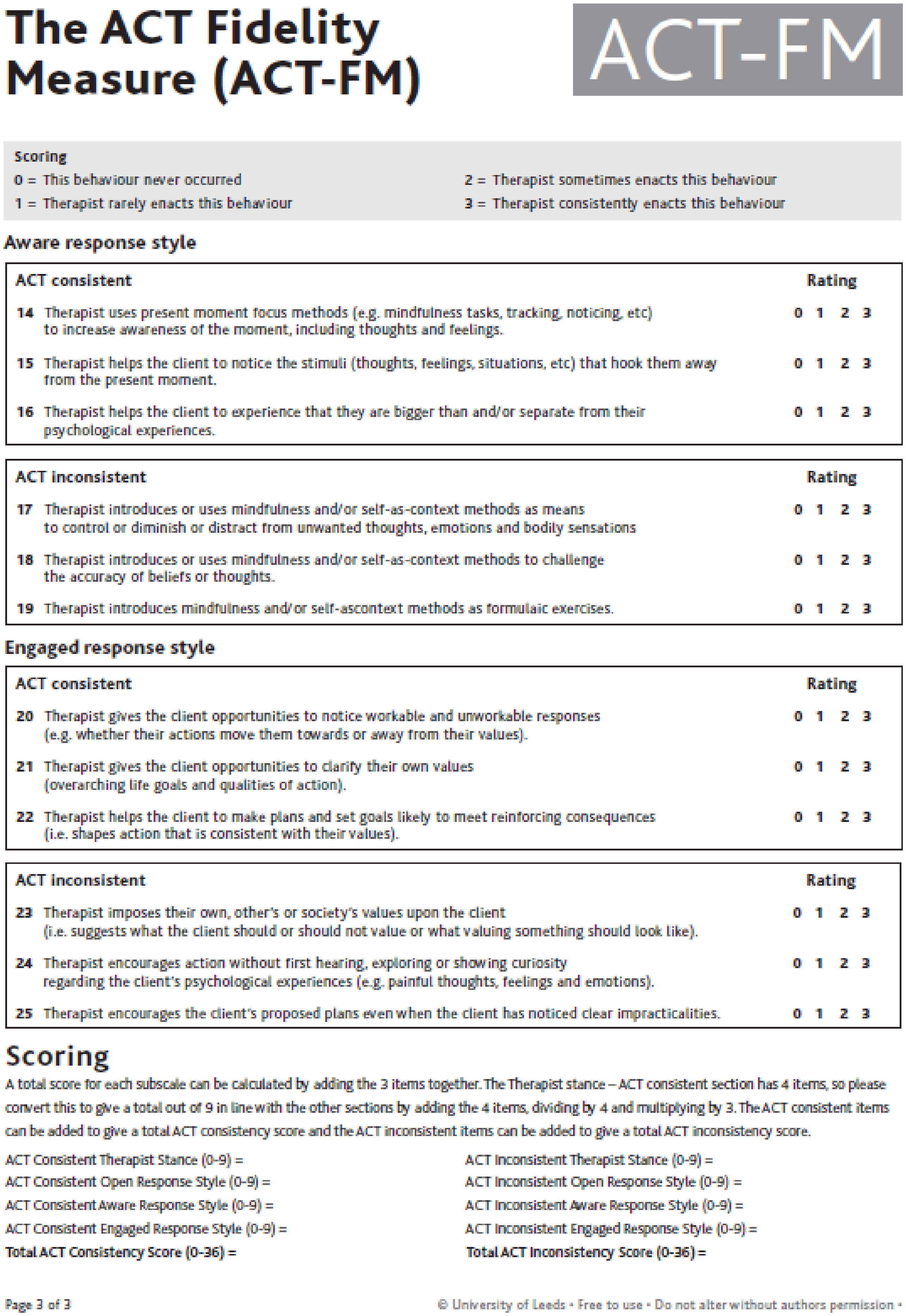
	ACT consistent	**Rating**
1	Therapist chooses methods that are sensitive to the situation and context (i.e. in a flexible and responsive way rather than a 'one size fits all' approach).	**0 1 2 3**
2	Therapist uses experiential methods/questions (i.e. helps the client to notice and use their own experience rather than thoughts about their experience).	**0 1 2 3**
3	Therapist conveys that it is natural to experience painful or difficult thoughts and feelings when one is in circumstances such as those experienced by the client.	**0 1 2 3**
4	Therapist demonstrates a willingness to sit with their own and the client's painful thoughts and feelings and the situations that give rise to these.	**0 1 2 3**

	ACT inconsistent	**Rating**
5	Therapist lectures the client (e.g. gives advice, tries to convince the client, etc).	**0 1 2 3**
6	Therapist rushes to reassure, diminish or move on from "unpleasant" or "difficult" thoughts and feelings when these arise.	**0 1 2 3**
7	Therapist conversations are at an excessively conceptual level (i.e. therapist overly emphasises verbal understanding of concepts rather than using experiential methods for behaviour change).	**0 1 2 3**

Open response style

	ACT consistent	**Rating**
8	Therapist helps the client to notice thoughts as separate experiences from the events they describe.	**0 1 2 3**
9	Therapist gives the client opportunities to notice how they interact with their thoughts and/or feelings (e.g. whether avoidant or open).	**0 1 2 3**
10	Therapist encourages the client to "stay with" painful thoughts and feelings (in the service of their values).	**0 1 2 3**

	ACT inconsistent	**Rating**
11	Therapist encourages the client to control or to diminish distress (or other emotions) as the primary goal of therapy.	**0 1 2 3**
12	Therapist encourages the client to "think positive" or to substitute negative for positive thoughts as a treatment goal.	**0 1 2 3**
13	Therapist encourages or reinforces the view that fusion or avoidance are implicitly bad, rather than judging them on basis of workability.	**0 1 2 3**



The ACT Fidelity Measure (ACT-FM)

ACT-FM

Scoring

0 = This behaviour never occurred	2 = Therapist sometimes enacts this behaviour
1 = Therapist rarely enacts this behaviour	3 = Therapist consistently enacts this behaviour

Aware response style

	ACT consistent	**Rating**
14	Therapist uses present moment focus methods (e.g. mindfulness tasks, tracking, noticing, etc) to increase awareness of the moment, including thoughts and feelings.	0 1 2 3
15	Therapist helps the client to notice the stimuli (thoughts, feelings, situations, etc) that hook them away from the present moment.	0 1 2 3
16	Therapist helps the client to experience that they are bigger than and/or separate from their psychological experiences.	0 1 2 3

	ACT inconsistent	**Rating**
17	Therapist introduces or uses mindfulness and/or self-as-context methods as means to control or diminish or distract from unwanted thoughts, emotions and bodily sensations	0 1 2 3
18	Therapist introduces or uses mindfulness and/or self-as-context methods to challenge the accuracy of beliefs or thoughts.	0 1 2 3
19	Therapist introduces mindfulness and/or self-ascontext methods as formulaic exercises.	0 1 2 3

Engaged response style

	ACT consistent	**Rating**
20	Therapist gives the client opportunities to notice workable and unworkable responses (e.g. whether their actions move them towards or away from their values).	0 1 2 3
21	Therapist gives the client opportunities to clarify their own values (overarching life goals and qualities of action).	0 1 2 3
22	Therapist helps the client to make plans and set goals likely to meet reinforcing consequences (i.e. shapes action that is consistent with their values).	0 1 2 3

	ACT inconsistent	**Rating**
23	Therapist imposes their own, other's or society's values upon the client (i.e. suggests what the client should or should not value or what valuing something should look like).	0 1 2 3
24	Therapist encourages action without first hearing, exploring or showing curiosity regarding the client's psychological experiences (e.g. painful thoughts, feelings and emotions).	0 1 2 3
25	Therapist encourages the client's proposed plans even when the client has noticed clear impracticalities.	0 1 2 3

Scoring

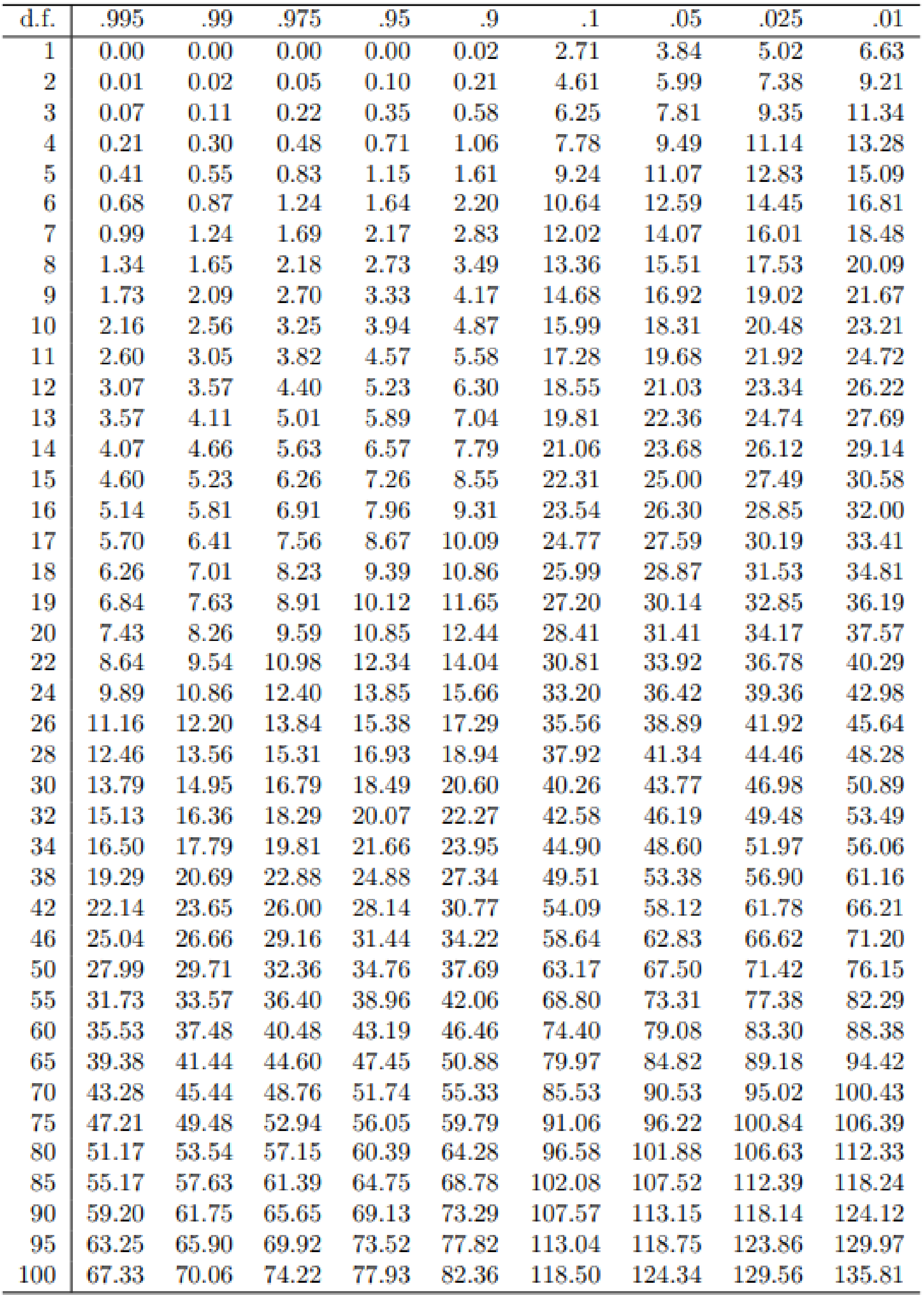
A total score for each subscale can be calculated by adding the 3 items together. The Therapist stance – ACT consistent section has 4 items, so please convert this to give a total out of 9 in line with the other sections by adding the 4 items, dividing by 4 and multiplying by 3. The ACT consistent items can be added to give a total ACT consistency score and the ACT inconsistent items can be added to give a total ACT inconsistency score.

ACT Consistent Therapist Stance (0-9) =
ACT Consistent Open Response Style (0-9) =
ACT Consistent Aware Response Style (0-9) =
ACT Consistent Engaged Response Style (0-9) =
Total ACT Consistency Score (0-36) =

ACT Inconsistent Therapist Stance (0-9) =
ACT Inconsistent Open Response Style (0-9) =
ACT Inconsistent Aware Response Style (0-9) =
ACT Inconsistent Engaged Response Style (0-9) =
Total ACT Inconsistency Score (0-36) =

Page 3 of 3

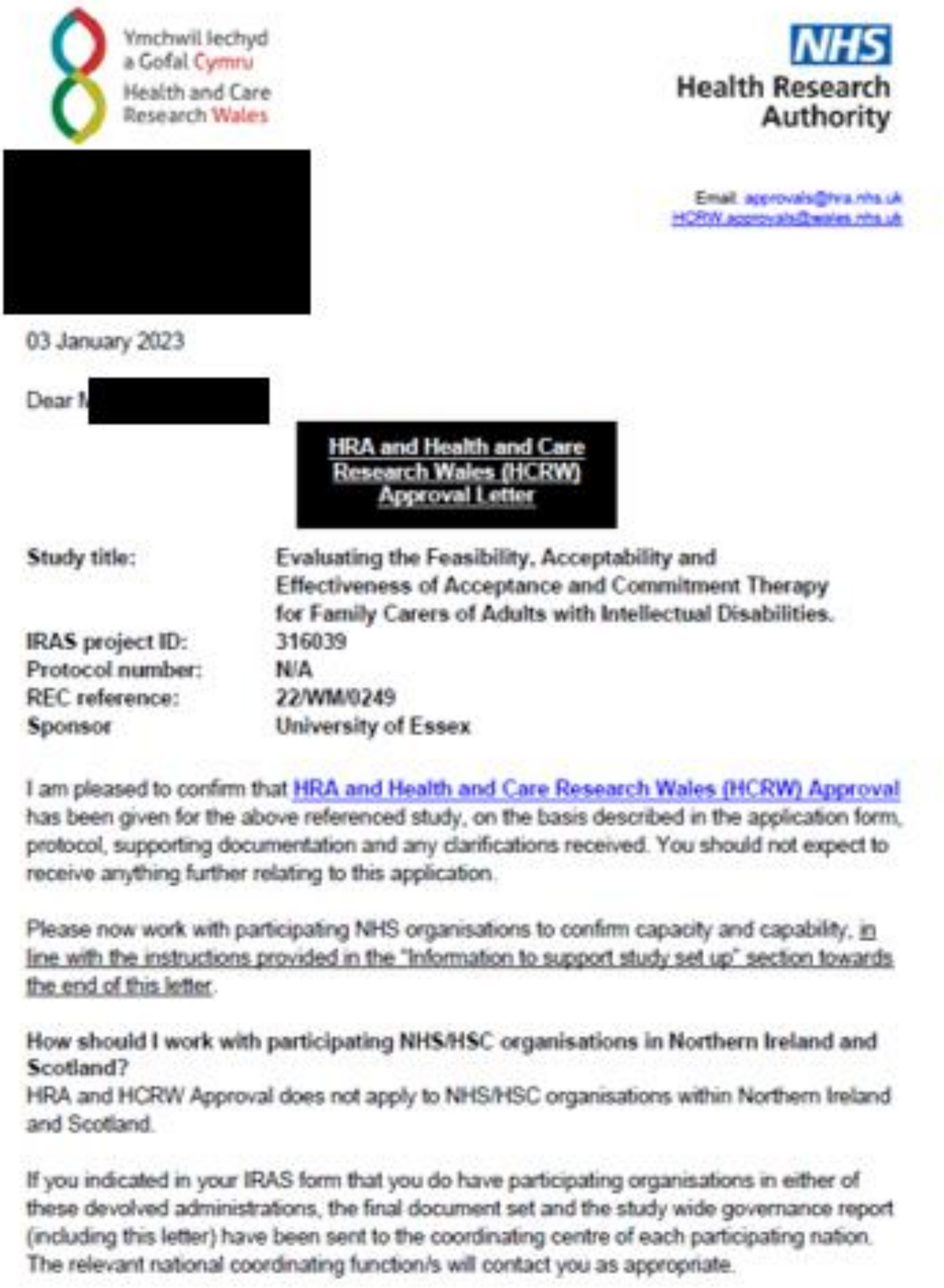
Appendix M
Chi-square Distribution Table



d.f.	.995	.99	.975	.95	.9	.1	.05	.025	.01
1	0.00	0.00	0.00	0.00	0.02	2.71	3.84	5.02	6.63
2	0.01	0.02	0.05	0.10	0.21	4.61	5.99	7.38	9.21
3	0.07	0.11	0.22	0.35	0.58	6.25	7.81	9.35	11.34
4	0.21	0.30	0.48	0.71	1.06	7.78	9.49	11.14	13.28
5	0.41	0.55	0.83	1.15	1.61	9.24	11.07	12.83	15.09
6	0.68	0.87	1.24	1.64	2.20	10.64	12.59	14.45	16.81
7	0.99	1.24	1.69	2.17	2.83	12.02	14.07	16.01	18.48
8	1.34	1.65	2.18	2.73	3.49	13.36	15.51	17.53	20.09
9	1.73	2.09	2.70	3.33	4.17	14.68	16.92	19.02	21.67
10	2.16	2.56	3.25	3.94	4.87	15.99	18.31	20.48	23.21
11	2.60	3.05	3.82	4.57	5.58	17.28	19.68	21.92	24.72
12	3.07	3.57	4.40	5.23	6.30	18.55	21.03	23.34	26.22
13	3.57	4.11	5.01	5.89	7.04	19.81	22.36	24.74	27.69
14	4.07	4.66	5.63	6.57	7.79	21.06	23.68	26.12	29.14
15	4.60	5.23	6.26	7.26	8.55	22.31	25.00	27.49	30.58
16	5.14	5.81	6.91	7.96	9.31	23.54	26.30	28.85	32.00
17	5.70	6.41	7.56	8.67	10.09	24.77	27.59	30.19	33.41
18	6.26	7.01	8.23	9.39	10.86	25.99	28.87	31.53	34.81
19	6.84	7.63	8.91	10.12	11.65	27.20	30.14	32.85	36.19
20	7.43	8.26	9.59	10.85	12.44	28.41	31.41	34.17	37.57
22	8.64	9.54	10.98	12.34	14.04	30.81	33.92	36.78	40.29
24	9.89	10.86	12.40	13.85	15.66	33.20	36.42	39.36	42.98
26	11.16	12.20	13.84	15.38	17.29	35.56	38.89	41.92	45.64
28	12.46	13.56	15.31	16.93	18.94	37.92	41.34	44.46	48.28
30	13.79	14.95	16.79	18.49	20.60	40.26	43.77	46.98	50.89
32	15.13	16.36	18.29	20.07	22.27	42.58	46.19	49.48	53.49
34	16.50	17.79	19.81	21.66	23.95	44.90	48.60	51.97	56.06
38	19.29	20.69	22.88	24.88	27.34	49.51	53.38	56.90	61.16
42	22.14	23.65	26.00	28.14	30.77	54.09	58.12	61.78	66.21
46	25.04	26.66	29.16	31.44	34.22	58.64	62.83	66.62	71.20
50	27.99	29.71	32.36	34.76	37.69	63.17	67.50	71.42	76.15
55	31.73	33.57	36.40	38.96	42.06	68.80	73.31	77.38	82.29
60	35.53	37.48	40.48	43.19	46.46	74.40	79.08	83.30	88.38
65	39.38	41.44	44.60	47.45	50.88	79.97	84.82	89.18	94.42
70	43.28	45.44	48.76	51.74	55.33	85.53	90.53	95.02	100.43
75	47.21	49.48	52.94	56.05	59.79	91.06	96.22	100.84	106.39
80	51.17	53.54	57.15	60.39	64.28	96.58	101.88	106.63	112.33
85	55.17	57.63	61.39	64.75	68.78	102.08	107.52	112.39	118.24
90	59.20	61.75	65.65	69.13	73.29	107.57	113.15	118.14	124.12
95	63.25	65.90	69.92	73.52	77.82	113.04	118.75	123.86	129.97
100	67.33	70.06	74.22	77.93	82.36	118.50	124.34	129.56	135.81

Appendix N

Health Research Authority and Health Research Wales Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

[redacted]

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

03 January 2023

Dear [redacted]

HRA and Health and Care Research Wales (HCRW) Approval Letter

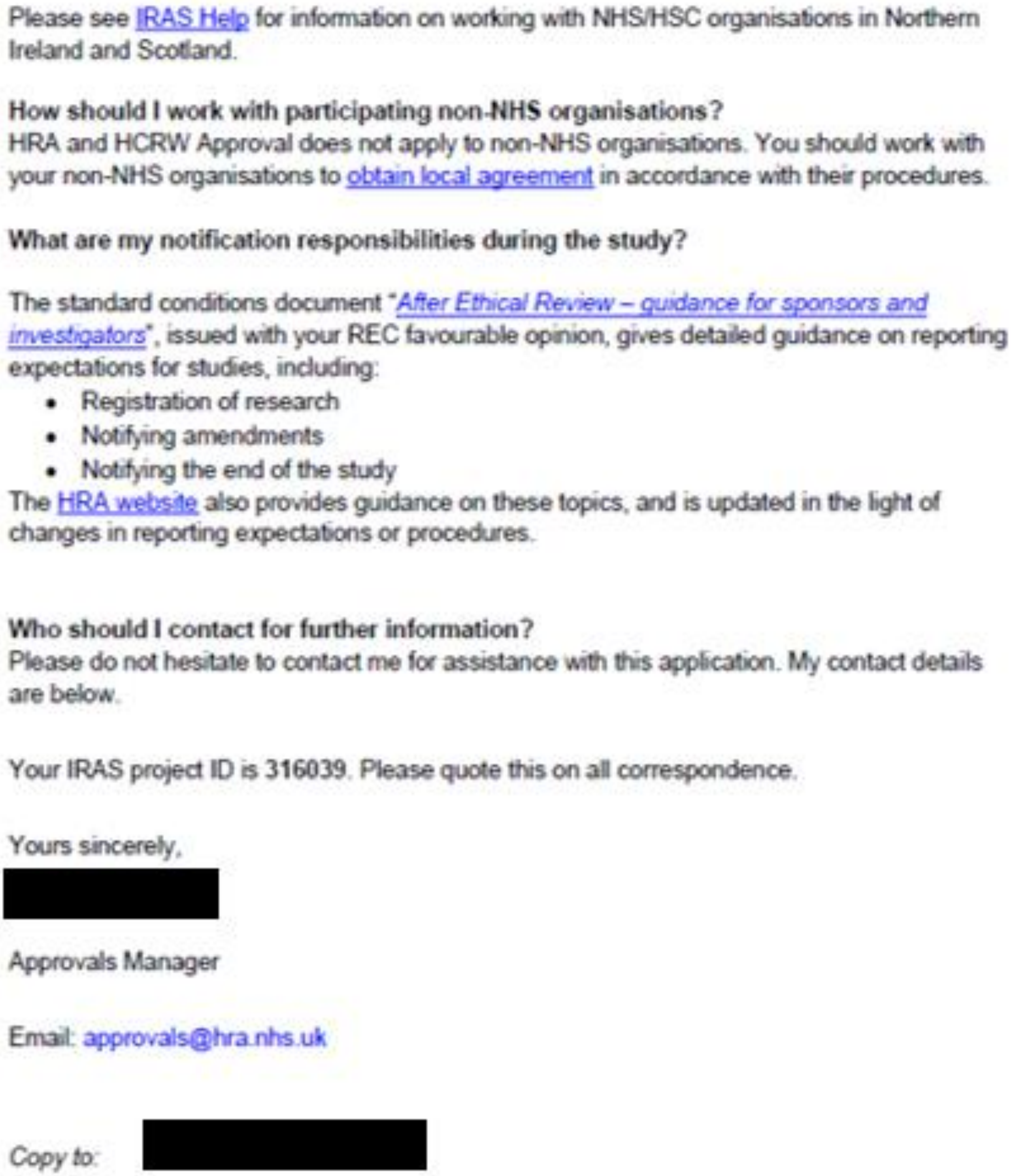
Study title:	**Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities.**
IRAS project ID:	316039
Protocol number:	N/A
REC reference:	22/WM/0249
Sponsor	University of Essex

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

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

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

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 316039. Please quote this on all correspondence.

Yours sincerely,

[redacted]

Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: [redacted]

IRAS project ID	316039

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

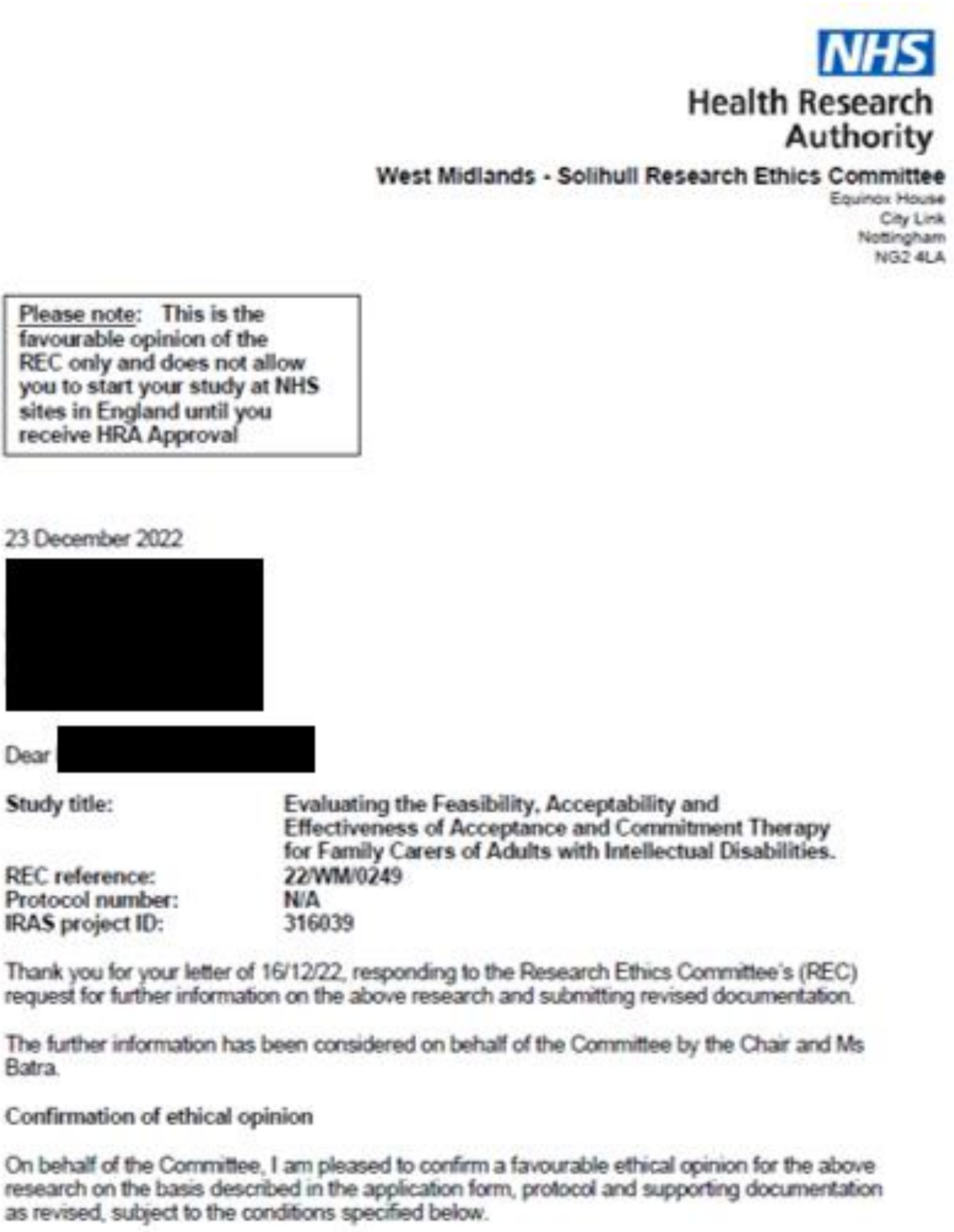
Types of participating NHS organisation	**Expectations related to confirmation of capacity and capability**	**Agreement to be used**	**Funding arrangements**	**Oversight expectations**	**HR Good Practice Resource Pack expectations**
There is one participating NHS organisation taking part in the study in England. Therefore, there is one site-type undertaking the research activities as detailed in the study protocol.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type.	The sponsor has detailed its proposals with respect to whether any study funding will be provided to participating NHS organisations of this type in the relevant Organisational Information Document. This should be read in conjunction with the relevant Schedule of Events/SoECAT which details the cost implications of the study for participating NHS organisations.	In line with HRA/HCRW expectations a Local Collaborator should be appointed at participating NHS organisations of this type.	Where an external individual will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold a Letter of Access. The pre-engagement checks should include a standard DBS check (including a check against the DBS 'barred list' for adults), and Occupational Health Clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix O

NHS REC Ethical Approval



NHS
Health Research
Authority

West Midlands - Solihull Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

23 December 2022

[redacted]

Dear [redacted]

Study title:	**Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities.**
REC reference:	**22/WM/0249**
Protocol number:	**N/A**
IRAS project ID:	**316039**

Thank you for your letter of 16/12/22, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

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

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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

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

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, ‘clinical trials’ are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

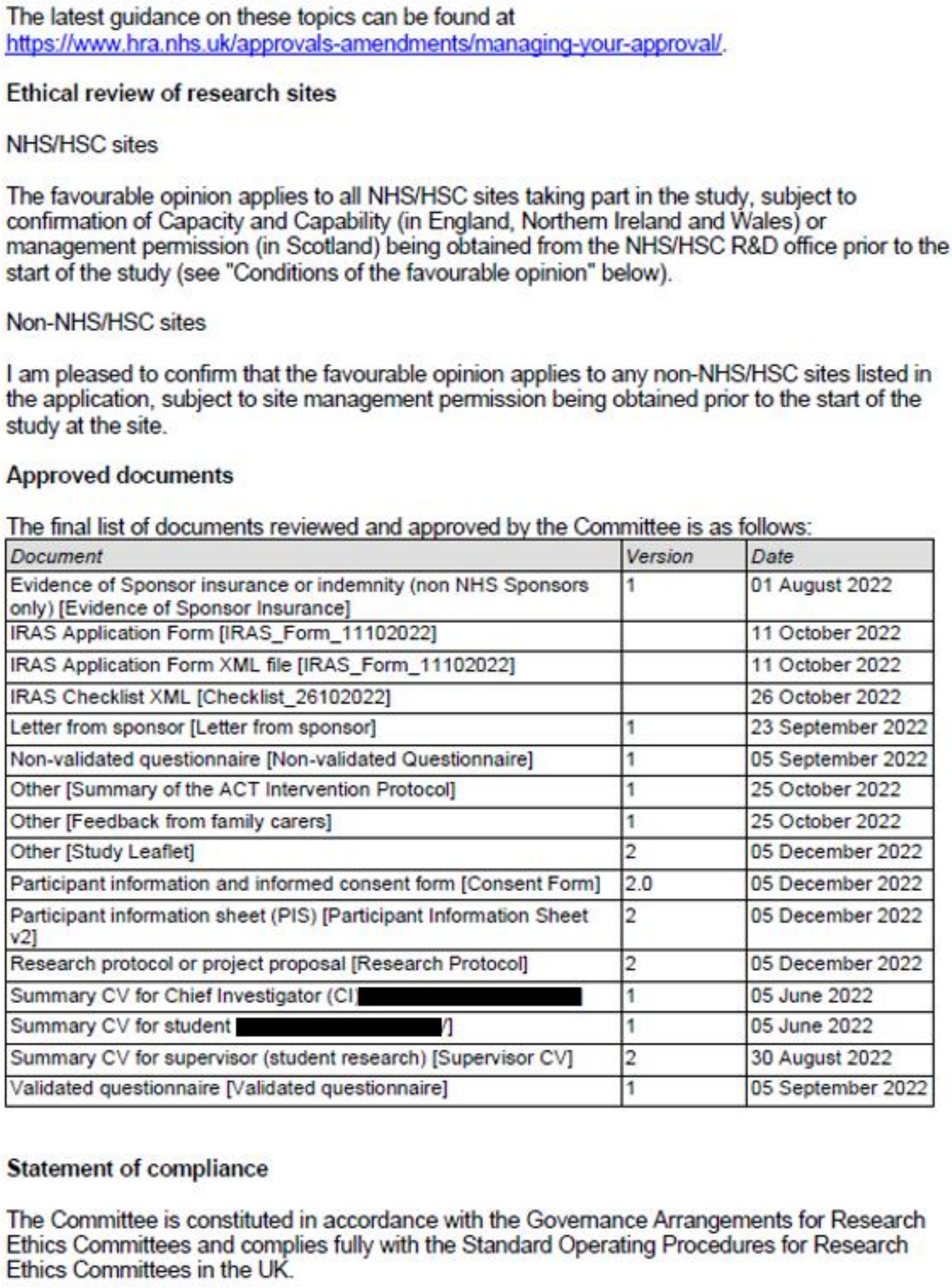
During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

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

After ethical review: Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results



The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

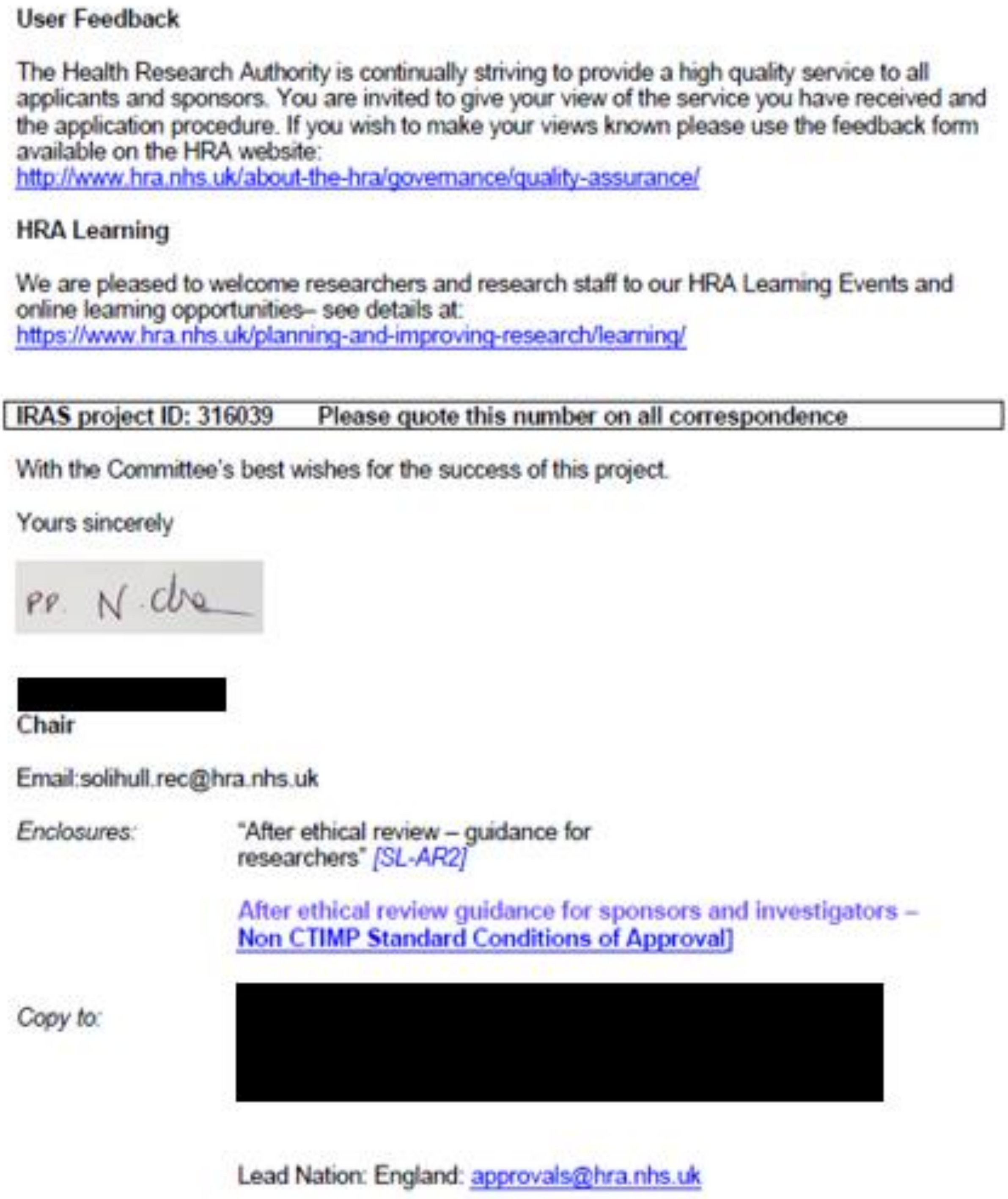
Approved documents

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

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]	1	01 August 2022
IRAS Application Form [IRAS_Form_11102022]		11 October 2022
IRAS Application Form XML file [IRAS_Form_11102022]		11 October 2022
IRAS Checklist XML [Checklist_26102022]		26 October 2022
Letter from sponsor [Letter from sponsor]	1	23 September 2022
Non-validated questionnaire [Non-validated Questionnaire]	1	05 September 2022
Other [Summary of the ACT Intervention Protocol]	1	25 October 2022
Other [Feedback from family carers]	1	25 October 2022
Other [Study Leaflet]	2	05 December 2022
Participant information and informed consent form [Consent Form]	2.0	05 December 2022
Participant information sheet (PIS) [Participant Information Sheet v2]	2	05 December 2022
Research protocol or project proposal [Research Protocol]	2	05 December 2022
Summary CV for Chief Investigator (CI[redacted]	1	05 June 2022
Summary CV for student [redacted]]	1	05 June 2022
Summary CV for supervisor (student research) [Supervisor CV]	2	30 August 2022
Validated questionnaire [Validated questionnaire]	1	05 September 2022

Statement of compliance

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



User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 316039 Please quote this number on all correspondence

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

Yours sincerely

pp. N. che

[redacted]
Chair

Email:solihull.rec@hra.nhs.uk

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

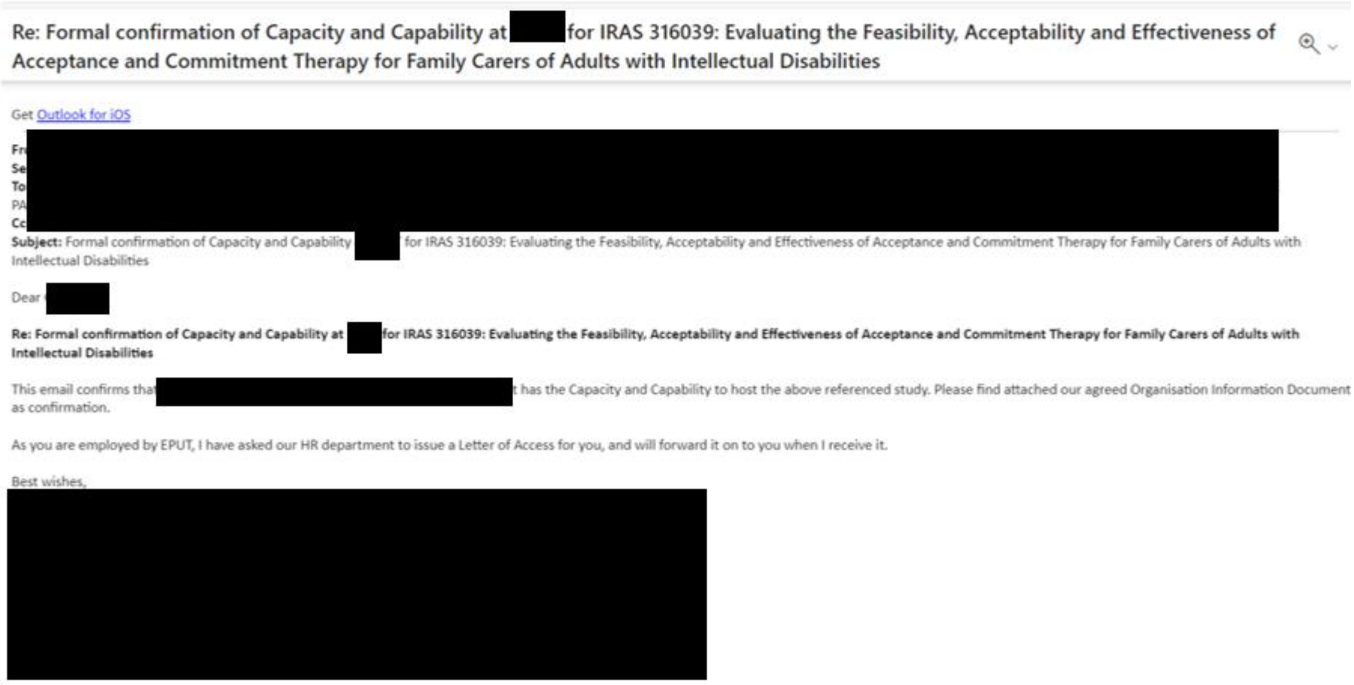
After ethical review guidance for sponsors and investigators – **Non CTIMP Standard Conditions of Approval]**

Copy to: [redacted]

Lead Nation: England: approvals@hra.nhs.uk

Appendix P

Confirmation of Capacity and Capability from NHS Trust



Re: Formal confirmation of Capacity and Capability at [redacted] for IRAS 316039: Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities

Get Outlook for iOS

[redacted]

Subject: Formal confirmation of Capacity and Capability [redacted] for IRAS 316039: Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities

Dear [redacted]

Re: Formal confirmation of Capacity and Capability at [redacted] for IRAS 316039: Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities

This email confirms that [redacted] has the Capacity and Capability to host the above referenced study. Please find attached our agreed Organisation Information Document as confirmation.

As you are employed by EPUT, I have asked our HR department to issue a Letter of Access for you, and will forward it on to you when I receive it.

Best wishes,

[redacted]

Appendix Q

University of Essex Ethical Approval

University of Essex

19/01/2023

[redacted]

Health and Social Care

University of Essex

[redacted]

Ethics Committee Decision Application: ETH2223-0718

We are writing to advise you that your application to register an external ethical approval of your research project entitled "Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities." has been reviewed by the REO Research Governance Team. We are pleased to inform you that the University of Essex will accept the ethical approval granted by HRA NHS REC for the project named above and you will not be required to make a full application for ethical approval through the University's ethics review process.

Please do not hesitate to contact the REO Research Governance Team (reo-governance@essex.ac.uk) if you require any further information or have any queries.

Yours sincerely,

REO Research Governance Team

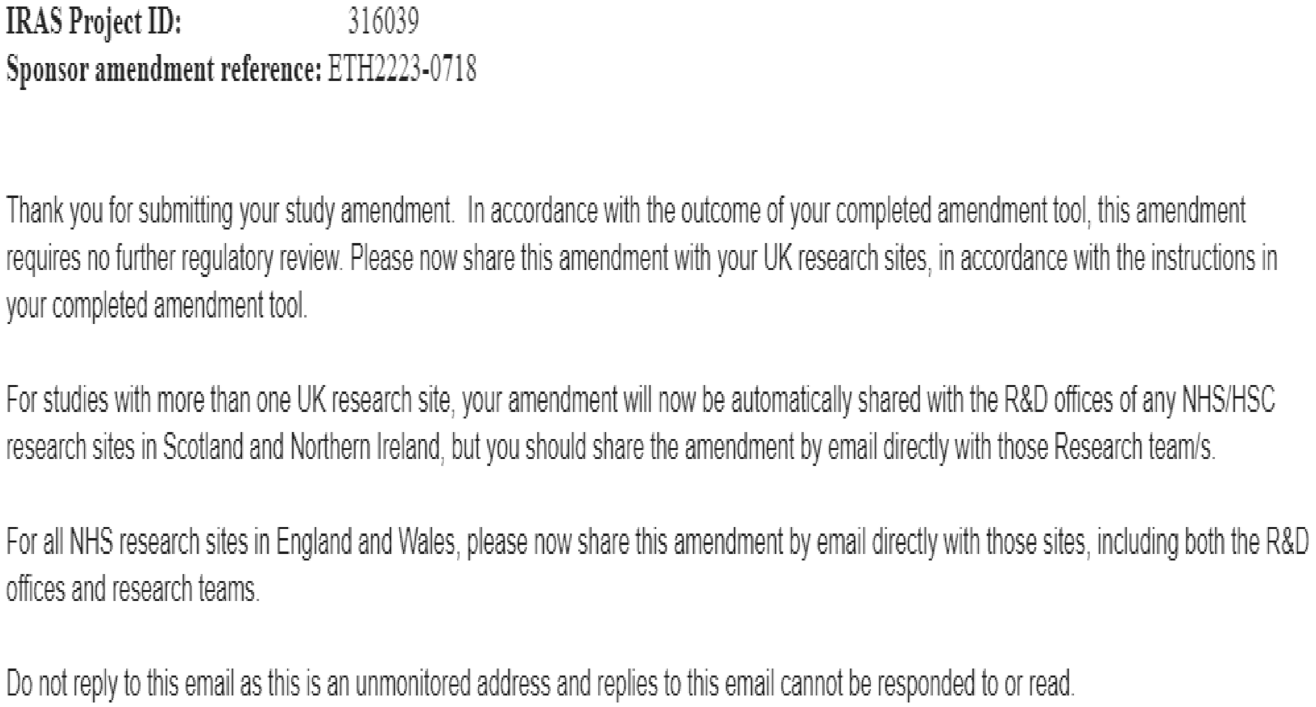
Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

T 01206 873333

www.essex.ac.uk
@Uni_of_Essex /uniofessex /uniofessex

Appendix R

NHS Ethics Amendment Confirmation Email



IRAS Project ID: 316039
Sponsor amendment reference: ETH2223-0718

Thank you for submitting your study amendment. In accordance with the outcome of your completed amendment tool, this amendment requires no further regulatory review. Please now share this amendment with your UK research sites, in accordance with the instructions in your completed amendment tool.

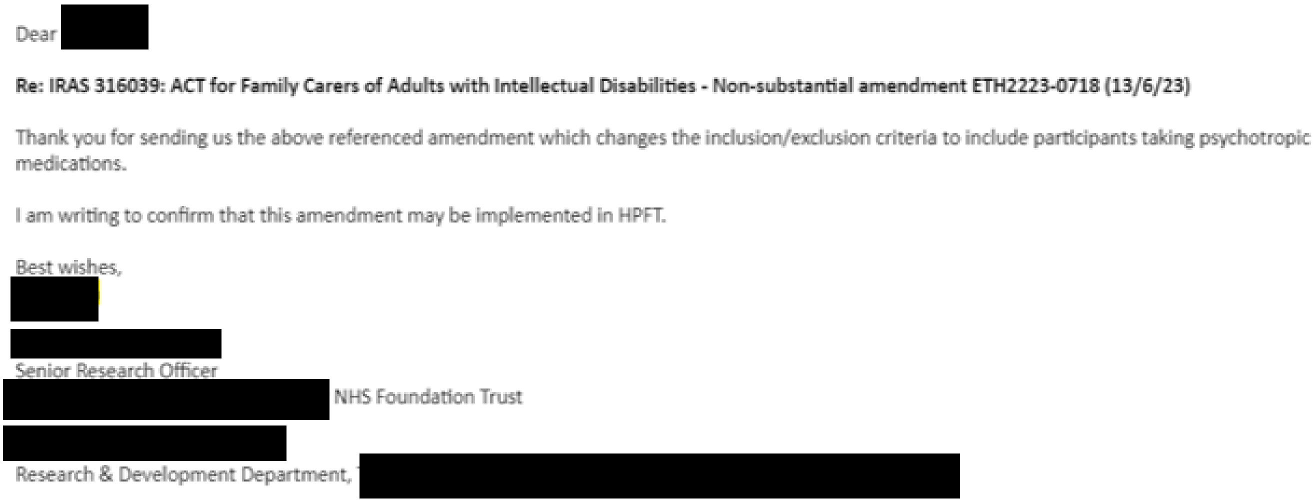
For studies with more than one UK research site, your amendment will now be automatically shared with the R&D offices of any NHS/HSC research sites in Scotland and Northern Ireland, but you should share the amendment by email directly with those Research team/s.

For all NHS research sites in England and Wales, please now share this amendment by email directly with those sites, including both the R&D offices and research teams.

Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.

Appendix S

Research and Development Department Amendment Confirmation Email



Dear [redacted]

Re: IRAS 316039: ACT for Family Carers of Adults with Intellectual Disabilities - Non-substantial amendment ETH2223-0718 (13/6/23)

Thank you for sending us the above referenced amendment which changes the inclusion/exclusion criteria to include participants taking psychotropic medications.

I am writing to confirm that this amendment may be implemented in HPFT.

Best wishes,
[redacted]

[redacted]
Senior Research Officer
[redacted] NHS Foundation Trust

[redacted]
Research & Development Department, [redacted]

Appendix T

Evidence of University of Essex Ethics Amendment Approval

[redacted]

Health and Social Care

University of Essex

Dear [redacted]

Ethics Committee Decision Application: ETH2223-2373

We are writing to advise you that your application to amend a registered external ethical approval of your research project entitled "Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities." has been reviewed by the REO Research Governance Team. We are pleased to inform you that the University of Essex will accept the ethical approval granted by HRA NHS REC for the project named above and you will not be required to make a full application for ethical approval through the University's ethics review process.

Please do not hesitate to contact the REO Research Governance Team (reo-governance@essex.ac.uk) if you require any further information or have any queries.

Yours sincerely,

REO Research Governance Team

Appendix U

Participant Information Sheet

Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities.

Dear Participant,

My name is [Name removed] and I am a Trainee Clinical Psychologist at the University of Essex. I am currently carrying out a piece of research entitled, Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities under the supervision of [Name removed] (Clinical Tutor/Lecturer, Thesis Supervisor) and [Name removed] (Lecturer, Thesis Supervisor).

This research will aim to investigate the effects of an Acceptance and Commitment Therapy (ACT) group on family carers of adults with Learning Disabilities (LDs) on their mental health, quality of life, experience of caregiving and psychological flexibility. ACT has evolved from Cognitive Behavioural Therapy and is a psychological model that focuses on accepting what you cannot change, but still living your life according to the values and goals that are important to you. There is existing research highlighting the benefits of ACT for other carer populations, however no research has been conducted on ACT for family carers of adults with LDs. It is hoped this project will help to address the gap in the research.

The study is part of my clinical psychology doctorate in the Department of Health and Social Care at the University of Essex.

This information sheet provides you with information about the study and your rights as a participant.

Am I eligible to take part?

If you are a family carer or guardian of an adult diagnosed with a learning disability who is under the care of the [Name Removed] Learning Disability Specialist Health Services, aged at least 18 years old and proficient in English, then you are eligible to take part.

What does taking part in the research involve?

The study will consist of attending a one-day workshop based on acceptance and commitment therapy (ACT). Participants are not required to have any previous knowledge of

ACT. Participants will have the choice to attend the workshop face-to-face in a large meeting at [Address removed] or virtually using the Trust's secure software. The group facilitators will try their best to accommodate participant's preferences and participants will be allocated to the intervention format (i.e. online or face-to-face) based on the order in which they were recruited. It is therefore possible that some parents may not have the option to choose between online or face-to-face if all the spaces have been allocated. It is possible that all participants may opt for an online or face-to-face group, and this will be facilitated where possible.

The group will last 6 hours and will be facilitated by [Name removed] (Thesis Supervisor, Clinical Psychologist) and [Name removed] (Clinical Psychologist). During the group, participants will be encouraged to participate in a number of exercises, discussions and activities. Participants will be asked to complete a range of questionnaires to collect data on three occasions (during the screening appointment, and 3 weeks and 3 months after the group). The first outcome measures will be completed during the screening appointment and the second outcome measures will be completed during the workshop. Participants will be given the choice to complete the latter two with the facilitator over the phone or to complete and return copies via email or post. Participants will also be asked to identify and record the daily frequency of two problematic behaviours to be decreased and two values-directed behaviours to be increased over 4 weeks (one week before the group to three weeks after the group).

Do I have to take part?

There is no obligation to take part in the study. It is entirely up to you. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to participate in the study and then change your mind in the future, you can withdraw at any point, you are free to stop participating in the group, or withdraw even after the data has been collected. This will not affect the NHS services that your family member receives. If you withdraw from the study, any data collected prior to dissemination will be deleted. If publications or reports have already been disseminated, these cannot be withdrawn, however, these will only contain anonymised and aggregated data.

What are the possible disadvantages of taking part?

Exploring the challenges and experiences of being a family carer may be emotionally difficult to discuss. At any point during the group you may decide not to answer any questions or participate and to withdraw at any time without giving a reason. In this instance, participants will be invited to attend a debrief session and invited to share their reflections about participating in the study if they would like to. All participants will be provided with Samaritans helpline and advised to contact them in the event of any urgent mental health difficulties. In addition to this, participants will be advised to contact their GP if they report any difficulties in relation to their physical and/or mental health. If required, the facilitators will sign-post participants to any additional services.

What are the possible benefits of taking part?

It is hoped that your participation will provide you with skills to help you cope more effectively with the potential challenges of being a carer and to live your life according to the values and goals that are important to you. You will also provide an opportunity to meet other family carers of adults with LDs. The findings of this research will help to understand the potential challenges faced by family carers of adults with LDs and ways to support carers to manage these. This information could be used to inform service developments within NHS services.

Will my taking part in this study be kept confidential?

All information collected will be kept securely and will only be accessible by the researcher, [Name removed], the facilitators, [Name removed] and [Name removed], and thesis supervisors, [Name removed] and [Name removed]. Confidentiality will only be breached if safeguarding concerns are raised. As part of the screening process, you will be asked to provide your name and asked to provide some demographic information for analysis purposes. After this, participants will be given a unique code to use to complete questionnaires. Data collected through this questionnaire will be aggregated and you will not be individually identifiable in any reports or publications from this research. The results from this study will be written up in a report for my Doctorate. Any identifiable information will be anonymised in the write-up. The findings will be shared with the Learning Disability Specialist Health Services via a verbal presentation and written report. The research report will also be submitted for publication in a peer-reviewed journal and/or possibly presented at a research conference. Participants will be invited to inform the facilitators during the group or email the group facilitators after the group if they would like to receive a summary of the research findings. The summary of the findings will be devised and shared via email or post in September – October 2023.

Who has approved this project?

This research project has been approved by the University Of Essex Ethics Committee, Health Research Authority and NHS Research Ethics Committee. Permission to complete this study was granted by the Research and Development office [NHS Trust name removed].

What happens if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the student and/or their supervisor (details below). If you remain unsatisfied and wish to make a formal complaint, please contact [Name and email removed] Research Governance and Planning Manager, who will advise you further.

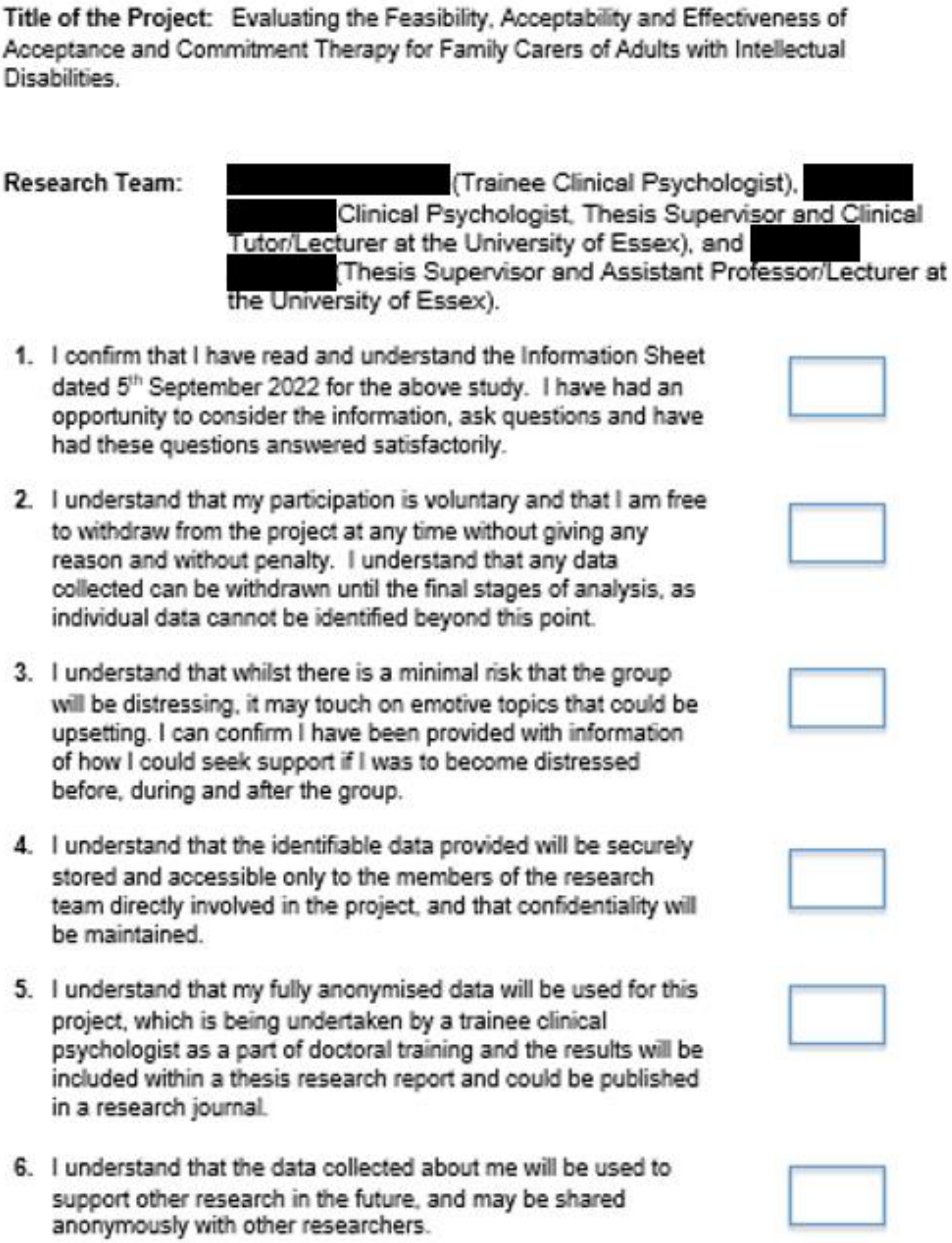
We would be very grateful for your participation in this study. If you need to contact us in future, please contact me on my email [Email removed], [Thesis supervisor name and email address removed] or [Thesis supervisor name and email address removed]. You can also contact us in writing at: [Name and address removed].

You are welcome to ask questions at any point.

Yours sincerely,

[Name removed], Trainee Clinical Psychologist

Appendix V
Participant Consent Form



Title of the Project: Evaluating the Feasibility, Acceptability and Effectiveness of Acceptance and Commitment Therapy for Family Carers of Adults with Intellectual Disabilities.

Research Team: [redacted] (Trainee Clinical Psychologist), [redacted] [redacted] Clinical Psychologist, Thesis Supervisor and Clinical Tutor/Lecturer at the University of Essex), and [redacted] [redacted] (Thesis Supervisor and Assistant Professor/Lecturer at the University of Essex).

1. I confirm that I have read and understand the Information Sheet dated 5th September 2022 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty. I understand that any data collected can be withdrawn until the final stages of analysis, as individual data cannot be identified beyond this point. ☐
3. I understand that whilst there is a minimal risk that the group will be distressing, it may touch on emotive topics that could be upsetting. I can confirm I have been provided with information of how I could seek support if I was to become distressed before, during and after the group. ☐
4. I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. ☐
5. I understand that my fully anonymised data will be used for this project, which is being undertaken by a trainee clinical psychologist as a part of doctoral training and the results will be included within a thesis research report and could be published in a research journal. ☐
6. I understand that the data collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I agree to take part in the above study. ☐

Participant Name	Date	Participant Signature
______________________	_________	______________________
Researcher Name	Date	Researcher Signature
______________________	_________	______________________

One copy will be provided to the participant and one copy will be kept for filing.

Appendix W

Participant Research Summary

Evaluating the Feasibility, Acceptability and Effects of Acceptance and Commitment Therapy for Family Carers of Adults with Learning Disabilities

Background:

- Acceptance and Commitment Therapy (ACT) has been shown to improve mental health and wellbeing outcomes for a range of informal caregivers, including family carers of individuals with dementia, autism, psychosis, acquired brain injury and children with learning disabilities (Fowler et al., 2021; Han et al., 2021; Magnacca et al., 2021; Reid et al., 2016).
- To date, there have been no studies exploring the effects of ACT on family carers of adults with learning disabilities.

Research Aims:

- This study investigated the effects of an ACT group on family carers of adults with learning disabilities in relation to their mental health, quality of life, experience of caregiving, psychological flexibility and problematic and values-based behaviours.

Methods:

- Sixteen family carers of adults with learning disabilities were recruited from an adult learning disability service.
- Family carers completed six questionnaires at three time points: during the screening appointment (time point one), 3 weeks after the workshop (time point two), and at 3 months follow-up (time point 3).
- Data analysis examined the differences in family carers’ scores across time based on group and individual scores.
- Family carers were invited to record the daily frequency of values-based and problematic behaviours over three to four weeks.
- Family carers provided feedback on the ACT workshop using a questionnaire.

Results:

- Statistical analysis revealed that there were no significant differences between depression, stress, anxiety, quality of life and positive aspects of caregiving scores across the three time points.
- Statistical analysis revealed that there were no significant differences between mindful states, cognitive fusion and psychological flexibility scores across the three time points.
- Statistical analysis of individuals’ scores revealed that the majority of family carers’ scores on seven outcomes did not change from time points one to three. Of the scores which did not remain stable, some family carers’ scores on the questionnaires deteriorated or improved over time.
- Ten family carers provided feedback on the ACT workshops.

- All ten family carers provided feedback on what they most liked about the intervention. For example, some family carers reported that they valued meeting and learning from other carers, and others made positive comments about the group facilitators.
- Family carers also provided constructive feedback about the ACT workshop. For example, some family carers thought it would be helpful to have more time to practise their ACT skills, and longer to interact with other carers.

Conclusions and Implications

- The results indicated that the ACT workshops did not result in significant improvements on the outcomes measured across time.
- However, these findings could be explained by the small sample size, and the lack of follow-up sessions and long-term follow-up data.
- Many family carers reported that they valued participating in the ACT workshop and meeting other carers.
- These findings add to the research on interventions for family carers and the challenges and experiences related to informal caregiving.
- As the first study within this area, further research is required to examine the effects and experiences of ACT on family carers of adults with learning disabilities.

References

Fowler, N. R., Judge, K. S., Lucas, K., Gowan, T., Stutz, P., Shan, M., Wilhelm, L., Parry, T., & Johns, S. A. (2021). Feasibility and acceptability of an acceptance and commitment therapy intervention for caregivers of adults with Alzheimer's disease and related dementias. *BMC geriatrics*, *21*(1), 1-10. https://doi.org/10.1186/s12877-021-02078-0

Han, A., Yuen, H. K., & Jenkins, J. (2021). Acceptance and commitment therapy for family caregivers: A systematic review and meta-analysis. *Journal of Health Psychology*, *26*(1), 82-102. https://doi.org/10.1177/1359105320941217

Magnacca, C., Thomson, K., & Marcinkiewicz, A. (2021). Acceptance and Commitment Therapy for Caregivers of Children with Neurodevelopmental Disabilities: a Systematic Review. *Current Developmental Disorders Reports*, *8*, 152–160. https://doi.org/10.1007/s40474-021-00228-y

Reid, C., Gill, F., Gore, N., & Brady, S. (2016). New ways of seeing and being: Evaluating an acceptance and mindfulness group for parents of young people with intellectual disabilities who display challenging behaviour. *Journal of Intellectual Disabilities*, *20*(1), 5-17. https://doi.org/10.1177/1744629515584868

Appendix X

SPSS Output for One-way Within-Subjects MANOVA

Multivariate[a,b]

Within Subjects Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Time_point	Pillai's Trace	.434	.762	16.000	44.000	.716	.217
	Wilks' Lambda	.601	.762[c]	16.000	42.000	.716	.225
	Hotelling's Trace	.607	.758	16.000	40.000	.719	.233
	Roy's Largest Root	.488	1.341[d]	8.000	22.000	.276	.328

a. Design: Intercept

Within Subjects Design: Time_point

b. Tests are based on averaged variables.

c. Exact statistic

d. The statistic is an upper bound on F that yields a lower bound on the significance level.

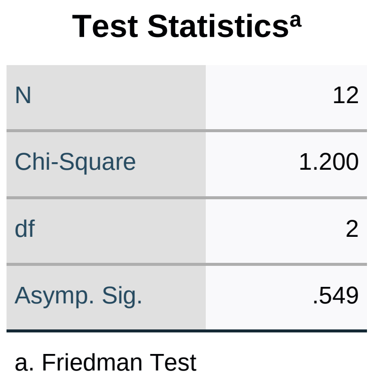
SPSS Output for Friedman Test on ACT Consistent Scores

Test Statistics[a]

N	13
Chi-Square	3.429
df	2
Asymp. Sig.	.180

a. Friedman Test

SPSS Output for Friedman Test on ACT Inconsistent Scores

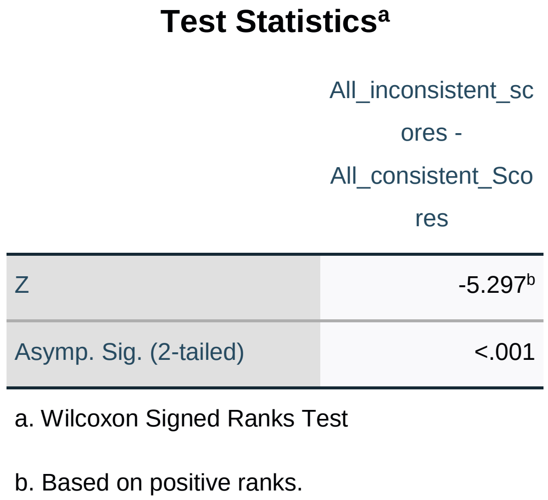


Test Statistics[a]

N	12
Chi-Square	1.200
df	2
Asymp. Sig.	.549

a. Friedman Test

SPSS Output for Wilcoxon Sign-Ranked Test on ACT Consistent and Inconsistent Scores



Test Statistics[a]

	All_inconsistent_scores - All_consistent_Scores
Z	-5.297[b]
Asymp. Sig. (2-tailed)	<.001

a. Wilcoxon Signed Ranks Test

b. Based on positive ranks.