Accepted on 30th May 2024 in the Journal of Child Psychology and Psychiatry Advances

Title: A Longitudinal study looking at the impact of COVID-19 restrictions and transitions on psychological distress in caregivers of children with Intellectual Disabilities in the UK.

Karri Gillespie-Smith¹, Karen Goodall¹, Doug McConachie¹, Jo Van Herwegen², Hayley Crawford³, Carrie Ballantyne⁴, Caroline Richards⁵, Thomas Gallagher-Mitchell⁶, Joanna Moss⁷, Grace Khawam¹, Laura Outhwaite2, Emily Marriott¹, Freyja Steindorsdottir¹ & Hope Christie¹

- 1. Department of Health and Clinical Psychology, School of Health in Social Science, University of Edinburgh.
- 2. Institute of Education, University College London.
- 3. Division of Health Sciences, Warwick Medical School, Warwick University.
- 4. Division of Psychology, School of Education and Social Science, University of West of Scotland.
- 5. School of Psychology, University of Birmingham.
- 6. Department of Psychology, Liverpool Hope University.
- 7. School of Psychology, University of Surrey.

Author Contact Details:

Karri Gillespie-Smith

Clinical & Health Psychology

School of Health in Social Sciences

Old Medical School, Teviot Place

University of Edinburgh

Telephone: (+44) 0131 651 3932

Email: <u>karri.gillespie-smith@ed.ac.uk</u>

Title: A longitudinal study of psychological distress during and after COVID-19 restrictions in caregivers of children with intellectual disability in the UK.

Abstract

Introduction: The current study explored longitudinally whether child behaviours that challenge and caregiver coping strategies was associated with psychological distress in caregivers of children with and without intellectual disability during and after lockdown.

Method: An online survey was completed by caregivers who had children with and without intellectual disability during Time Period 1 (T1; August-December 2021, n = 171) and then again during Time Period 2 (T2; January-March 2022, n = 109).

Results: Child behaviours that challenge and caregiver psychological distress reduced in T2 compared to T1. Child behaviours that challenge, emotion focused coping and avoidant coping was associated distress at both time points in caregivers of children with and without intellectual disabilities.

Conclusions: The study shows that both child behaviours that challenge and caregiver psychological distress reduced as lockdown ended. However, caregiver coping strategies may have contributed to psychological distress, which has implications for interventions and support for caregivers.

Keywords: Intellectual Disabilities; COVID-19; Longitudinal; Coping; Mental Health.

1. Introduction

The first UK wide Coronavirus (COVID-19) lockdown to reduce the spread of the virus (Cabinet Office, 2020) occurred from March to June 2020, followed by a second lockdown in Wales from October to November 2020, and in England and Northern Ireland from November to December 2020 (Baker et al., 2021; Senedd Research, 2022; SPICe Spotlight, 2022). The final full lockdown started in Wales and Northern Ireland in December 2020, joined by Scotland and England in January 2021 and ended in March 2021 (Baker et al., 2021; Senedd Research, 2022; SPICe Spotlight, 2022). While the specific restrictions and timing of lockdowns varied between the UK nations of England, Scotland, Wales, and Northern Ireland, the main

lockdown restrictions were similar throughout the UK, including rules such as reductions in gatherings, movement, and limited services (Ferguson et al., 2021). Legal restrictions on gatherings, travel and enforced social isolation continued throughout 2021 with all restrictions finally lifting in January 2022 for Scotland (Scotland to lift most remaining COVID-19 restrictions, 2022); February 2022 for England and Northern Ireland (COVID-19: Remaining restrictions in NI are lifted, 2022; UK Health Security Agency, 2022), and Wales in May 2022 (Culbertson, 2022).

1.1. Child Behaviours that Challenge

During COVID-19 lockdown, subgroups of families already disadvantaged by health inequalities were at higher risk of poorer mental health outcomes than others. One of these disadvantaged family groups included families who have children with intellectual disability (Diaz et al., 2021). Intellectual disability is characterised by social, cognitive, and adaptive skill difficulties (Zayac & Johnston, 2008), manifesting as self-injury, sexually or socially inappropriate behaviours, physical and/or verbal aggression, disturbed sleep, over or in activity, and destructive tendencies (Benson, & Brooks, 2008; Myrbakk & Von Tetzchner, 2008). These behaviours have also been referred to in the literature as 'challenging behaviours' or 'behaviours that challenge' (Myrbakk & Von Tetzchner, 2008). The National Institute for Health and Care Excellence (NICE, 2015) highlights that behaviours that challenge do not constitute a diagnosis, and may serve an important purpose to the individual with an intellectual disability (e.g., communication or sensory stimulation). Despite this, some of these behaviours (specifically self-injury and aggressive outbursts) can present persistent difficulties for family, carers, practitioners, and services. In addition, the health inequalities these children face pre-date COVID-19 and include, poorer general health, psychiatric disorders, and higher rates of emotional and behavioural difficulties compared to their typically developing peers (Allerton et al., 2011; Emerson & Einfeld, 2010). Disruption to routine and reduction in access to enjoyed activities (situations such as those observed during COVID-19 lockdown) are known to further exacerbate behaviours that challenge, which may also cause the development of other mental health difficulties including psychological distress (Borthwick-Duffy, 1994; NICE guidelines – NG11; published May, 2015).

1.2. Caregiver psychological distress

Parenthood and caregiving are often characterised by constant change that is driven by the developmental stage of the child (O'Connor, 2002) indicating that caregivers must always be adaptive to the child's needs. In addition, parents and caregivers experience more negative responses to disasters compared to those with fewer caregiving responsibilities (e.g. Fussell & Lowe, 2014) indicating that caregiving groups are at heightened risk of poorer outcomes during times of adversity. Caregivers of children who have intellectual disability specifically, are a vulnerable group who are more likely to develop mental health difficulties compared to carers of typically-developing children (Gallagher et al., 2008; Herring et al., 2006). Social support and the severity of the disability, psychiatric disorder and child's levels of challenging behaviours are all key factors that contribute to caregiver psychological distress (e.g., Blacher & McIntyre, 2006; Unwin & Debb, 2011; Weiss, 2002; White & Hastings, 2004). Management of challenging behaviours impacts both the individuals' quality of life and opportunities (e.g., social, education, career) but also poses a significant additional burden on caregivers, leading to increased stress levels (Blacher & McIntyre, 2006; McConnell & Savage 2015). Perceived burden includes guilt, resentment, embarrassment, isolation, and loss of control (Zarit et al., 1980), with guilt being the strongest predictor of anxiety and depression in caregivers of children with intellectual disability (Gallagher et al., 2008). COVID-19 has been reported to have significantly increased the perceived levels of strain and burden in caregivers who have children with Special Educational Needs and Disabilities (SEND) (Dhiman et al., 2020).

Respite services and social support are crucial for reducing caregiver stress and burnout (Dunn et al., 2001; Sherman, 1995), with research indicating that caregivers who have high levels of social support show better psychological adjustment (Duis et al., 1997; Dunn et al., 2001). Contrastingly, greater distress is reported in families who perceive high caregiver burden and limited social support (Dunn et al., 2001; Gallagher et al., 2008). Therefore, significant reductions in educational, clinical and respite services for children with intellectual disabilities during COVID-19 presented significant challenges to caregivers (Neece et al., 2020; O'Hagan & Kingdom, 2020) and some of these reductions have continued despite the easing of lockdown measures (Gillespie-Smith et al., 2022).

1.2.1. Caregiver coping

Previous research has suggested that disruption to routines and restrictions impact how caregivers perceive their situation and influences the coping strategies they employ (Cramm

& Nieboer, 2011). According to general stress and coping theory (e.g., Lazarus & Folkman 1984) parents of children who have intellectual disability adapt to external situations using individual coping strategies (e.g., Hastings et al 2005). Coping is context dependent (Carver et al., 1989); therefore, interaction between stress and the contextual environment will affect the development of coping strategies (Hastings et al., 2005). To date, research has reported coping strategies that positively impact mental health outcomes in carers of children with intellectual disability, include active emotional coping (Ganjiwale et al., 2016); cognitive reframing and acceptance (Hastings et al., 2002; O' Donnchadha, 2018); and positive reinterpretation (Smith, et al., 2008). In the literature three ways of coping are often presented: (i) problem-focused coping, which refers to actively eliminate sources of stress and manage stressful events; (ii) emotion-focused coping, which includes efforts to reduce the emotional consequences of stressful situations; (iii) avoidant coping, which indicates physical or cognitive efforts to disengage from the stressful event or situation (Dias et al., 2012; Folkman, 2008). Research to date has shown that problem-based coping strategies are related to good mental health, and emotion-based or avoidant coping strategies are correlated with poor mental health (Lloyd & Hastings, 2008; Macdonald, 2011; Smith et al., 2008). The way in which caregivers deal with stressful events can ultimately present a risk for, or protect them against, poor mental health outcomes.

In addition, caregiver distress is significantly associated with an increase in behavioural and emotional problems in children with intellectual difficulties (Bailey et al., 2021; Totsika et al., 2020). To our knowledge, only one study to date has looked at both child challenging behaviours and caregiver distress in the same UK based sample during COVID-19 (Gillespie-Smith et al., 2021). They found that parents of children with intellectual disability who utilised high levels of avoidant coping strategies, such as denial and behaviour disengagement, went on to show higher levels of psychological distress. As this was a cross-sectional study, reports of child and caregiver distress are limited to only one time-point during the COVID-19 lockdown.

1.3. Current Study

The current study aimed to extend the research carried out by Gillespie-Smith et al. (2021) by exploring longitudinally whether caregiver coping strategies continued to relate to mental health in caregivers of children with intellectual disability during and after the COVID-19 UK

lockdown. The current study looks more specifically at how coping strategies associated with types of caregiver psychological distress (stress, anxiety, and depression). The following hypotheses were posed;

- 1. That socio-demographic factors such as caregiver education level and employment status would be related to caregiver coping, stress, anxiety and depression.
- 2. Due to the unprecedented nature of the pandemic, and lack of control over events, it was predicted that higher levels of avoidant, problem focused and emotion focused coping, would be observed during lockdown (T1) compared to after lockdown (T2) and that all coping strategies would be higher for caregivers who have children with Intellectual disabilities compared to caregivers who have children who are typically developing.
- 3. It was also predicted that caregiver distress (stress, anxiety and depression) would be significantly higher during lockdown (T1) compared to after lockdown (T2), and that all domains of distress would be higher for caregivers who have children with Intellectual disabilities compared to caregivers who have children who are typically developing.
- 4. It was predicted that child challenging behaviours would be significantly higher during Lockdown (T1) compared to after Lockdown (T2) and that behaviours that challenge would be reported to be higher in the caregiver group who have children with Intellectual disabilities compared to the caregiver group who have children who are typically developing.
- It was further predicted that child challenging behaviours would be related to caregiver stress, anxiety and depression as well as caregiver coping strategies (avoidant, problem focused and emotion focused) during T1 and T2.
- 6. Finally, it was predicted that higher levels of avoidant and emotion focused coping and lower levels of problem focused coping would predict higher levels of stress, anxiety and depression in caregivers during both time periods.
- 2. Methods
- 2.1. Participants

Participants were parents or caregivers (hereafter referred to as 'caregivers') of a child with or without an intellectual disability between 5-19 years old. Both caregivers of neurotypical children and children who have intellectual disabilities were recruited through research adverts posted on social media platforms (Facebook and Twitter). Caregivers of children with intellectual disabilities were additionally recruited through UK based charity (e.g. Down Syndrome Foundation, ENABLE, Scottish Autism, National Autistic Society, Williams Syndrome Foundation) and parent groups (e.g. Kindred, Parent and Carer Alliance) by sharing the study advert via charity websites, newsletters or mailing lists. To be included in the current sample, caregivers were required to be 16 years and above, understand the English language, and live in the UK. To reduce the risk of bot or false responses, participants had to first contact the researcher and tell them where they had seen the study advert, provide their child's birthday, whether they had disability and if so provide information about their disability. Participants were then sent a link to take part in the survey during Time Period 1 (T1; August-December 2021) and the same caregivers were invited via email to take part in the survey again during Time Period 2 (T2; January-March 2022). No participants declined to take part in T1 however 62 participants did not complete the follow up T2 survey (despite three reminder emails being sent). Only participants that took part in T1 were invited to take part in T2. 182 participants took part in T1 survey initially, however during data inspection, n = 11 responses were judged to be invalid (64% of these were completed in less than 900 seconds, and 36% were responses from a matching IP address). The final sample included 171 participants in T1 and 109 participants in T2. Independent samples t-tests were carried out to check whether the participants who did not take part in T2 significantly differed from those who did take part in T2 based on the key variables, parental distress, coping strategies and levels of child behaviours that challenge. There were no significant differences. See Table 1 for sociodemographic characteristics of the caregivers and their children for the intellectual disability and the group reporting no intellectual disabilities during the two time points (hereafter referred to as 'typically-developing'). Despite the caregiver groups being randomly recruited, the final sample sizes numbers were relatively similar.

A description of the intellectual disabilities group diagnoses for T1 can be found in Table 2. A G-power calculation based on regression analyses with 8 predictors (controlling for variables

gender and age of child), with a moderate effect size of 0.3 indicated that a sample of n = 107 was required. The final sample sizes at both time points remained within these parameters.

2.2. Procedure

Following ethical approval granted from the University of XXXX Ethics Committee, participants were recruited online (via online social networking sites, charity websites, and parent group pages). To take part parents had to contact the researcher who then sent them a direct link to the online survey hosted by Qualtrics Survey system which took approximately 45 - 50 minutes to complete. After clicking a link, participants were first presented with the participant information screen, followed by the consent screen before entering the survey battery. Due to the sensitive nature of the survey (i.e. psychological distress), mental health support information was provided throughout the survey including the participant information screen, and again at the end within the debrief screen. Participants were also informed that they were free to stop at any point (with no negative repercussions) by closing the computer window.

2.3. Measures

2.3.1. Survey on COVID-19

A questionnaire was developed, comprising 40 demographic data items (caregiver age, child age, marital status, employment status, number of siblings etc.) in addition to categorical questions on the impact of COVID-19 and how the government restrictions had impacted their family situation, living arrangements, and services/respite support. The survey took approximately 10 minutes to complete and was completed in T1 data collection only. Following this, data were transformed to numerical form, by applying scoring schemes to the nominal data so these could be inputted to parametric tests. This T1 data was linked to the T2 data using email addresses. Caregivers were then asked to complete the following psychometric scales during the two time periods.

2.3.2. Caregiver psychological distress

The Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond 1995), a self-report questionnaire consisting of 21 items, with 7 items per subscale: stress, anxiety and depression. Participants are asked to score every item on a 3-point Likert scale from 0 (did not apply to

me at all) to 3 (applied to me very much), and scores from each item were added to obtain a total for each subscale. Numerous studies have reported favourable psychometric properties of the DASS in adults with anxiety and/or mood disorders in both community and clinical samples (Antony et al., 1998; Clara, et al., 2001). DASS subscale scores were used as a measure of stress, anxiety and depression with higher scores indicating increased severity (Beaufort, et al., 2017). Studies have demonstrated excellent internal consistency of the DASS-21 items, ranging from .81 - .97 (Gloster, et al., 2008). In the current study, the DASS-21 displayed robust internal consistency at Time 1 (a=.91) and Time 2 (a=.94).

2.3.3. Child Behaviours that Challenge

The Developmental Behaviour Checklist - P24 (DBC – P24; Taffe, et al., 2007) is a 24-item checklist which is a shorter form of the DBC which is a 96-item scale (Einfeld & Tonge 1994; 1995) specifically designed to assess behavioural and emotional disturbance in children/adolescents with intellectual disability. The instrument has 24 items (e.g., over-excitement, impatience, and lack of affection) that are scored based on a three-point Likert scale from 0 (not true) to 2 (very true). The DBC-P24 performs very well in terms of low bias and high precision in cross-validation and displays excellent sensitivity and specificity properties (Taffe et al., 2007). A total Child Challenging Behaviour score was calculated by summing the scores with higher scores indicating higher levels of child 'challenging behaviours'. In the current study, the DBC-P24 displayed robust internal consistency at Time 1 (a=.91) and Time 2 (a=.91).

2.3.4. Caregiver Coping Strategies

The Brief COPE (Carver, 1997) a shortened version of the COPE, asks 28 questions on a fourpoint Likert scale, ranging from 1 (I haven't been doing this at all) to 4 (I've been doing this a lot), where two items each form 14 sub-scales with the totals of each subscale indicating how often the coping strategy is used. Each subscale has shown good internal consistency indicated by the Cronbach's alpha values ranging from 0.50 to 0.90 (Carver, 1997). In the current study, the Brief COPE displayed robust internal consistency at Time 1 (a=.84) and Time 2 (a=.85). The subscales include active coping, planning, positive reframing, acceptance, humour, turning to religion, using emotional support, using instrumental support, selfdistraction, denial, venting, substance use, behavioural disengagement, and self-blame. This scale has been used widely in groups of caregivers of children with intellectual disability and developmental disorders (e.g., Ganjiwale et al., 2016; Isa et al., 2017; Panicker et al., 2019). The scale provided information on each caregiver's abilities to cope, perceived social support and self-regulation. Higher scores reflect a higher tendency to implement the specified coping strategies.

These coping strategies were divided up to form three key coping strategies based on the three-factor model of Brief COPE (Dias et al., 2012) which has also shown good validity (Poulus et al., 2020). These three factors include (1) problem-focused coping, (2) emotion-focused coping, and (3) avoidant coping. Problem focused coping consists of active coping, instrumental support, planning and positive reframing. These coping strategies are aimed at changing the stressful situation and high scores are indicative of psychological strength. Emotion focused coping is characterised by venting, use of emotional support, humour, acceptance, self-blame, and religion. Higher scores indicate coping strategies that aim to regulate emotions associated with the stressful event. Finally, avoidant coping is characterised by the facets of self-distraction, denial, substance use, and behavioural disengagement. Higher scores on this coping strategy indicate physical or cognitive efforts to disengage from the stressful event or situation. Lower scores within this category are therefore indicative of adaptive coping.

2.4. Data Analysis

Normality was assessed using the Shapiro-Wilk test which showed that for both time points (Time 1 and Time 2) child behaviours that challenge, avoidant coping, caregiver stress, anxiety and depression significantly departed from normality (ps<.05). Listwise deletion was used for missing data. Visual inspections of histograms and Q-plots showed that the data were positively skewed, however, the skewness was still within typical parameters (all less than 1). Square root transformations were still applied before Pearson Correlations were carried out separately for each group (caregivers of children with intellectual disability and typically developing children). Correlations were carried out to highlight significant relationships between Demographics, Coping Strategies and Caregiver Psychological Distress. Bonferroni corrections for multiple comparisons were also applied throughout. Mixed 2x2x3 ANOVAs were carried out with between subject variable being Group (Caregivers of children who have

ID vs Caregivers of typically developing children) and within subject variable being Timepoints (T1 vs T2) and Caregiving Coping (Avoidant vs Emotion Focused vs Problem Focused). Similarly Mixed 2x2x3 ANOVAs were carried out with between subject variable being Group (Caregivers of children who have ID vs Caregivers of typically developing children) and within subject variable being Timepoints (T1 vs T2) and Caregiver Mental Health Outcome (Stress, Anxiety and Depression). Mixed 2x2 ANOVA was also carried out with between subject factor being Group (Caregivers of children who have ID vs Caregivers of typically developing children) and within subject being Timepoints (T1 vs T2) with dependent variable being Child Behaviours that challenge. Significant interactions were further explored with post-hoc independent samples t-tests. To understand whether coping strategies associated with poor caregiver mental health, pearson correlations were carried out (with bonferroni corrections applied for multiple comparisons) highlighting coping variables that had significant relationships with Caregiver Stress, Anxiety and Depression. Significant variables were taken forward into multiple linear regressions analyses. A series of six hierarchical regression analyses were conducted, to determine the independent effect of group (ID or TD), level of child behaviours that challenge and specific coping strategies on caregiver stress, anxiety and depression. In each model, group was entered as a dichotomous variable at step 1, child behaviour (DBC scores) at step 2 and coping strategy at step 3. The two significant coping strategies (avoidant and emotion focused) were then entered for stress, anxiety and depression outcome variables. Multiple analyses were conducted to avoid inter-collinearity with coping strategies and caregiver distress domains.

- 3. Results
- 3.1. Descriptive statistics

[Table 1 and Table 2 here]

3.1.1 Demographic data

There were no significant correlations between demographic data, child behaviours that challenge, caregiver coping and caregiver psychological distress (see Table 3).

[Table 3 here]

3.2. Caregiver Coping between Groups and between Timepoints

Mixed ANOVA showed that there was a significant effect of Timepoint F(1, 107) = 5.391, p = .022, Np^2 = .048, SE = .427, indicating that there were higher levels of coping strategies during T1 (m = 4.374, SE = .050) compared to T2 (m = 4.153, SE = .060). There was no significant interaction between Timepoint and Group F (1, 107) = .002, p = .967, Np^2 = .000, SE = .051). There was a significant effect of Coping F (2, 192) = 402.027, p <.001, Np^2 = .790, SE = .529. Paired samples t-tests revealed that caregivers engaged in Avoidant Coping (m = 3.736, SE = .036 significantly less compared to Problem Focused Coping (m = 4.052, SE = .050) t (170) = 5.283, p <.001, d =.782., and Emotion Focused Coping (m = 5.039, SE = .040), t(170) = 32.388, p <.001, d = .526. Emotion Focused Coping was the strategy most used by caregivers, with them engaging in this strategy significantly more than Problem Focused Coping t (170) = 21.507, p <.001, d = .601. There was no significant interaction between Group and Coping showing that both groups employed similar coping strategies F (2, 192) = 1.003, p = .361, Np^2 = .009. There was a significant interaction between Timepoint and Coping F (2, 189) = 20.082, p < .001, $Np^2 = .158$. To explore this significant interaction paired samples t-tests were carried out which showed that the only significant difference was Problem Focused Coping which was significantly higher in T1 (m = 4.365, SE = .047) compared to T2 (m = 3.654, SE = .084), t (143) = 8.626, p <.001, d = .990. There was no significant interaction between Timepoint, Coping and Group F(2, 189) = 1.848, p = .165, Np^2 = .017. There was no overall significant effect of Group F(1, 108) = .575, p = .450, $Np^2 = .005$.

3.3. Caregiver Psychological Distress between Groups and between Timepoints

Mixed ANOVA showed that there was a significant effect of Timepoint F (1, 107) = 247.196, p < .001, Np^2 = .698, SE = 1.154, indicating that there were higher levels of psychological distress during T1 (m = 3.731, SE = .064) compared to T2 (m = 2.434, SE = .113). There was no significant interaction between Timepoint and Group F (1, 107) = .118, p = .732, Np^2 = .001. There was a significant effect of Psychological Distress F (2, 201) = p <.001, Np^2 = .401. Paired samples t-tests were carried out to explore this significant effect and it showed that caregivers experienced lower levels of Anxiety (m = 3.023, SE = .069) compared to Stress (m = 3.299, SE = .058) t (170) = 9.063, p <.001, d = .397 and Depression (m = 3.320, SE = .068) t (170) = 6.103, p <.001, d = .635. There was no significant interaction between Group and Caregiver Distress F (2, 201) = .146, p = .852, Np^2 = .001. There was a significant interaction between Timepoint and Distress F (2, 208) = 8.034, p <.001, Np^2 = .070. Paired samples t-tests were carried out

to explore this significant interaction. Stress was found to be significantly higher in T1 (m = 4.040, SE= .063) compared to T2 (m = 2.876, SE = .106), t (108) = 13.325, p <.001, d = .912; Anxiety was also significantly higher in T1 (m = 3.469, SE = .063) compared to T2 (m = 2.012, SE = .121) t (108) = 15.329, p <.001, d = .992; and Depression was significantly higher during T1 (m = 3.684 SE = .066) compared to T2 (m = 2.414, SE = .113) t (108) = 13.372, p <.001, d = .992. There was no significant interaction between Timepoint, Distress and Group F (2, 208) = .200, p = .813, Np^2 = .002. There was an overall significant effect of Group F (1, 107) = 8.004, p = .006, Np^2 = .070, indicating that the Group of Caregivers who have Children with ID showed higher Distress (m = 3.337, SE = .079) compared to Caregivers who have Typically Developing Children (m = 3.077, SE = .091).

3.4. Child Challenging Behaviours between Groups and between Timepoints

The ANOVA showed that there was a significant effect of Timepoint F(1, 107) = 1208.532, p <.001, Np^2 = .919 indicating that the children showed higher levels of behaviours that challenge during T1 (m = 6.256, SE = .079) compared to T2 (m = 3.774, SE = .128). There was a significant interaction between Group and Timepoint F (1, 107) = 9.919, p =.002, Np^2 = .085. Independent Samples t-tests highlighted that the Caregivers of Children with Intellectual Disabilities reported significantly higher levels of child challenging behaviours during T1 (m = 6.661, SE = .093) compared to T2 (m = 4.391, SE = .141) t (57) = 26.742, p <.001, d = .647. There was a significant difference in levels of challenging behaviours in the caregivers who had typically developing children during T1 (m = 5.795, SE = .099) compare to T2 (m = 3.073, SE = .177), t (50) = 22.892, p <.001, d = .849. There was also an overall effect of Group F (1,107) = 40.692, p <.001, Np^2 = .276, indicating that Caregivers of children with Intellectual Disabilities (m = 5.526, SE = .171) reported significantly higher level of Challenging behaviours compared to caregivers of children who are typically developing (m = 4.434, SE = .190).

3.5. Correlations

3.5.1 Time 1

Intellectual disabilities group: Child challenging behaviours were positively associated with the following caregiver measures: stress (r = .441, p < .001, SE = .086), anxiety (r = .519, p < .001, SE = .078) depression (r = .446, p < .001, SE = .086), avoidant coping (r = .477, p < .001, SE = .083) and emotion focused coping (r = .341, p < .001, SE = .013). Similarly, caregiver stress

levels were associated with avoidant coping (r = .449, p < .001, SE = .086), emotion focused coping (r = .372, p < .001, SE = .092). Caregiver anxiety level was associated with avoidant coping (r = .573, p < .001, SE = .072), and emotion focused coping (r = .390, p < .001, SE = .091). Depression was associated with avoidant coping only (r = .526, p < .001, SE = .078).

Typically-developing group: Child challenging behaviours were positively associated with caregiver stress (r = .323, p = .003, SE = .102), anxiety (r = .427, p < .001, SE = .093) and depression (r = .409, p < .001, SE = .094). There was also a positive association between child behaviours that challenge and caregiver avoidant Coping (r = .470, p < .001, SE = .088). Caregiver stress was also positively associated with avoidant coping (r = .538, p < .001, SE = .081) and emotion focused coping (r = .372, p < .001, SE = .098). Caregiver anxiety and depression were related to avoidant coping only (r = .542, p < .001, SE = .080; r = .591, p < .001, SE = .074 respectively).

3.5.2 Time 2

Intellectual disabilities group: There was a significant positive association between child behaviours that challenge and caregiver anxiety (r = .496, p<.001, SE = .102); as well as caregiver avoidant coping strategies (r = .377, p = .004, SE = .116). Caregiver distress was also related to several coping strategies; caregiver stress was positively associated with avoidant coping (r = .382, p = .003, SE = .115) and emotion focused coping (r = .380, p = .003, SE = .115). Caregiver anxiety was related to avoidant coping (r = .373, p = .004, SE = .116); and emotion focused coping (r = .380, p = .003, SE = .115). Caregiver anxiety was related to avoidant coping (r = .373, p = .004, SE = .116); and emotion focused coping (r = .371, p = .004, SE = .116). Depression was related to avoidant coping only (r = .470, p = .004, SE = .105).

Typically-developing group: In the typically developing group child behaviours that challenge were positively associated with caregiver anxiety (r = .386, p = .005, SE = .123), and caregiver avoidant coping (r = .460, p < .001, SE = .114) and emotion focused coping (r = .464, p < .001, SE = .113). In addition, caregiver stress (r = .405, p < .001, SE = .121), Anxiety (r = .460, p < .001, SE = .114); and depression (r = .568, p < .001, SE = .098) were all positively associated with caregiver avoidant coping only.

3.6 Regression analyses

3.6.1 Time 1

Caregiver Stress

Table 4 displays the results of the hierarchical regression where group was added at step 1, child behaviour at step two and avoidant coping at step 3. The first model with Group being added was significant , F(1, 169) = 7.440, p = .007, SE = .103. The addition of child behaviour in model 2 explained an additional 14% of variance in caregiver stress, after controlling for group, $\Delta R^2 = 0.14$, F change = 27.822 (2, 168), p < .001, SE = .066. In the final model, avoidant coping was statistically significant, F change = 29.441 (1, 167), p < .001, SE = .099. The final model explains 30% of the variance in caregiver stress $R^2 = .30$. Table 2 also shows the same analysis with emotion focused coping replacing avoidant coping. results of the next significant model with emotion focused coping being added at Step 3, F(1, 167) = 16.503, p < .001, SE = .009. This model explains 25% of the variance ($R^2 = .25$).

[Table 4 here]

Caregiver Anxiety

Table 4 also displays the results of the hierarchical regression where group was added at step 1, child behaviour at step two and avoidant coping at step 3. The first model with Group being added was significant , F(1, 169) = 6.658, p = .011, SE = .102. The addition of child behaviour in model 2 explained an additional 21% of variance in caregiver anxiety, after controlling for group, $\Delta R^2 = 0.21$, *F* change = 47.354 (2, 168), P < .001, SE = .063. In the final model, avoidant coping was statistically significant, F change = 37.718. (1, 167). *p* <.001. SE = .092. The final model explains 39% of the variance in caregiver anxiety $R^2 = .39$. Another significant model emerged when emotion focused coping was added at Step 3 *F* (1, 167) = 4.607, *p* = .033, explaining 27% of the variance ($R^2 = .27$) – see Table 4.

Caregiver Depression

Table 4 displays the results of the hierarchical regression where group was added at step 1, child behaviour at step two and avoidant coping at step 3. The first model with Group being added was significant , F(1, 169) = 4.498, p = .035, SE = .109. The addition of child behaviour scores in model 2 explained an additional 18% of variance in caregiver depression, after controlling for group, $\Delta R^2 = 0.18$, F change = 37.024 (2, 168), P < .001, SE = .068. In the final

model, avoidant coping was statistically significant, *F* change = 42.055 (1, 169), p < .001, SE = .099. The final model explains 36% of the variance in caregiver depression ($R^2 = .36$).

3.5.2 Time 2

Caregiver Stress

Table 5 displays the results of the hierarchical regression where group was added at step 1, child behaviour at step two and avoidant coping at step 3. The first model with Group being added was not significant, F(1, 107) = 3.232, p = .075, SE = .209. The addition of child behaviour scores in model 2 explained an additional 10% of variance in caregiver stress, after controlling for group, $\Delta R^2 = 0.10$, F change = 12.734 (2, 106), P < .001, SE = .086. In the final model, only avoidant coping was statistically significant, F change = 13.011 (1, 107), p <.001, SE = .224. The final model explains 23% of the variance in caregiver stress $R^2 = .23$. Table 5 also shows the next significant model with emotion focused coping being added at Step 3, F(1, 107) = 16.503, p < .000. This model explains 7.4% of the variance (Adjusted $R^2 = .074$).

[Table 5 here]

Caregiver Anxiety

Table 5 displays the results of the hierarchical regression where group was added at step 1, child behaviour at step two and avoidant coping at step 3. The first model with Group being added was not significant, F(1, 107) = 3.820, p = .053, SE = .240. The addition of child behaviour scores in model 2 explained an additional 19% of variance in caregiver anxiety, after controlling for group, $\Delta R^2 = 0.19$, F change = 25.316 (2, 106), P < .001, SE = .093. In the final model, avoidant coping was statistically significant, F change = 7.024 (1, 105), p = .009, SE = .250. The final model explains 27% of the variance in caregiver anxiety $R^2 = .27$). Table 5 also shows that another significant model emerged when emotion focused coping was added at Step 3 F (1, 105) = 6.609, p = .012, SE = .021, explaining 27% of the variance ($R^2 = .27$).

Caregiver Depression

Table 5 displays the results of the hierarchical regression where group was added at step 1, child behaviour at step two and avoidant coping at step 3. The first model with Group being

added was not significant, F(1, 107) = 3.558, p = .062, SE = .224. The addition of child behaviour scores in model 2 explained an additional 8% of variance in caregiver depression, after controlling for group, $\Delta R^2 = 0.08$, F change = 9.831 (2, 106), p < .001, SE = .093. In the final model avoidant coping was statistically significant, F change = 18.415, p < .001, SE = .237. The final model explains 25% of the variance in caregiver depression $R^2 = .25$).

4. Discussion

The current study is the first study to look at both child challenging behaviours and caregiver distress in families with and without children who have intellectual disability during and after lockdown in the UK. It was predicted that socio-demographic factors such as caregiver education level and employment status would be related to caregiver coping, stress, anxiety and depression. There were no significant associations between demographics, caregiver coping and caregiver psychological distress. This is in contradiction to other research which has found that caregivers who are younger, or on lower incomes reported increased psychological distress during Covid-19 (Beach, Schulz, Donovan, & Rosland, 2021; Russell, et al., 2020). It is worth noting that these discrepancies may be due to the stage of Covid-19 lockdown that data was collected as well as the country. Beach et al., (2021) and Russell et al., (2020) were carried out at an earlier stage of the covid-19 pandemic in the United States. Further research is needed to better understand the role of demographics on caregiver coping and distress across different countries throughout the different covid-19 transition periods.

It was predicted that higher levels of avoidant, problem focused and emotion focused coping, would be observed during lockdown compared to after lockdown. This was supported since there was a significant effect of Timepoint indicating that caregivers showed higher levels of all coping behaviours during Covid-19 (i.e. T1) compared to after Covid-19 (T2). Paired samples t-tests also showed that caregivers engaged in Avoidant Coping least and engaged in more Emotion Focused coping. As mentioned previously Avoidant coping and Emotion Focused coping can lead to poorer mental health outcomes (e.g. Macdonald, 2011), therefore this shows that coping strategies may be a useful area to target for intervention and help support caregivers during difficult times. Covid-19 timepoint was also found to interact with problem focused coping only with caregivers reporting higher levels of this coping during T1 compared to T2. This is often reported as an adaptive coping strategy that can lead to better

wellbeing in parents regardless of child behaviours (e.g. Smith et al., 2008) so it was encouraging to see that the current sample of caregivers defaulted to this strategy during the intense period of Covid-19 Lockdown.

Another hypothesis was that psychological distress would be higher in all caregivers during Covid-19 (T1) compared to after Covid-19 (T2) which was supported by the results. Similar results have been reported in other countries for e.g. Johnson et al., 2022 reported increased levels of caregiver distress in Norway during lockdown/school closure periods. All caregivers in the current study also showed significantly higher levels of Stress and Depression compared to Anxiety. Depression specifically in caregivers during Covid-19 has been found in other literature (Gallagher & Wetherell, 2020) and is thought to be caused by the high levels of loneliness experienced during the pandemic. Lack of social support and socialising opportunities may lead to intense periods of being with the family with little respite, and this may have also increased caregiver's perceived burden causing higher levels of Stress, Anxiety and Depression were higher for all caregivers during T1 compared to T2 indicating that similar to other Covid-19 research that caregiver psychological distress increased during Lockdown (Willner et al., 2020).

It is worth noting before going further that although this study aimed to explore differences between caregivers of children who have and do not have Intellectual Disabilities, both groups showed similarities in coping strategies during and after Covid-19. This is an interesting result given the additional barriers and issues that families with children who have intellectual disabilities face (e.g., Blacher & McIntyre, 2006; Unwin & Debb, 2011). This may show that the impact of COVID-19 lockdown was relative to the family context before and during the pandemic and was viewed by all families to increase levels of coping strategies and psychological distress. Another between group finding was that caregivers of children with ID showed higher levels of psychological distress compared to caregivers of typically developing children. Again this is similar to previous research showing that caregivers who have children with more complex needs show higher levels of distress during the pandemic (lovino, Caemmerer & Chafouleas 2021; Willner et al., 2020) and supports the notion that this is a vulnerable group who are more at risk of negative mental health outcomes.

It was proposed that child behaviours that challenge would be significantly higher during lockdown compared to after lockdown. This was supported in the current study since all factors significantly reduced in the transition period following lockdown. This is in line with other cross-sectional research carried out in other countries such as China (Chen et al., 2021) which found significantly higher child mental health difficulties and behaviours that challenge during periods of school suspension. Relatedly it was also found that parents of children who have Intellectual Disabilities reported higher levels of behaviours that challenge. This makes sense since Intellectual disabilities are often characterised by adaptive, cognitive and social skill difficulties (Zayac & Johnston, 2008) which are associated with behaviours that challenge (Lee, et al., 2008) impacting on caregiver stress (McConnell & Savage 2015).

It was also predicted that higher levels of child behaviours that challenge would be related to caregiver distress during both time points (T1: during lockdown vs T2: after lockdown). Higher levels of child behaviours were found to be related to higher levels of caregiver stress, anxiety and depression in both caregiver groups (caregivers who have children with and without intellectual disability) at time1. Higher levels of child behaviours that challenge continued to be related to higher levels of caregiver anxiety in both caregiver groups at time 2, which is in line with previous research reporting the interdependent relationship between child behaviours that challenge and caregiver mental health outcomes (Baker et al., 2003; Blacher & McIntyre, 2006; Floyd & Gallagher, 1997). The children's levels of behaviours being related to more caregiver psychological distress at T1 may have been caused by the increased time spent together within close proximity. The easing of lockdown may have allowed more time to be spent separately either by returning to the workplace, school, or engaging in more lone leisure time, reducing levels of distress in caregivers and children' behaviours that challenge.

It was further proposed that child behaviours would be related to higher levels of all caregiver coping strategies (avoidant, problem focused and emotion focused). In the typically-developing group child behaviours that challenge were related to avoidant coping (e.g. self-distraction, denial, behavioural disengagement) during T1 and both avoidant and emotion focused coping (e.g. venting, use of emotional support, humour) during T2. For the caregivers

of children with intellectual disability, child behaviour was related to both avoidant and emotion focused coping at T1 and avoidant coping at T2. This is similar to other research such as Petrocchi et al., (2020) who found relationships between mothers' coping abilities during COVID-19 lockdown and children's adaptive behaviours through the mediation of child positive emotions. Although the Petrocchi et al., (2020) study demonstrates a similar relationship in the opposite direction compared to the current study findings. Taken together, both studies show a complex bi-directional relationship between child behaviours and caregiver coping that needs to be considered in all coping research.

It was also predicted that higher levels of avoidant and emotion focused coping and lower levels of problem focused coping would be associated with higher levels of stress, anxiety and depression during both time periods. Child behaviours that challenge and caregiver coping was shown to be significantly related to psychological distress in both groups at both time points. Child behaviours were found to be significantly related to all psychological distress outcome measures (stress, anxiety and depression) at both time points. Additionally, it was found that levels of avoidant coping and emotion focused coping was associated with caregiver stress and anxiety in both caregiver groups in Time 1 and Time 2. Only avoidant coping was associated with depression at both time points. The regressions also showed that avoidant coping explained higher levels of variance with stress, anxiety and depression at two time points indicating that this coping strategy may be an important catalyst in caregiver psychological distress. Interestingly, this is both similar and different to research carried out by Fluharty et al. (2021) in the general UK population during the first 21 weeks of lockdown. They found that avoidant coping predicted poorer mental health outcomes (depression and anxiety) and emotion focused coping led to improved outcomes which deviates from the current study findings that high levels of both coping types were associated with psychological distress. These slight differences might have been caused by the current study focusing on psychological distress measures as opposed to mental health outcomes or it may indicate that as lockdown continued some coping strategies that were adaptive to start with became maladaptive over the long term.

Interestingly, problem-focused coping did not explain significant variance in psychological distress. This does not align with other research carried out on caregivers, for example Smith

et al., (2008) found that problem focused coping was associated with better maternal wellbeing. This difference may be because the current study focused on psychological distress as opposed to wellbeing and may indicate that coping is associated with distress and wellbeing differently. In addition, earlier analysis also showed that problem focused coping was the only coping strategy that significantly reduced in T2 compared to T1. A potential explanation, since problem-focused coping refers to 'actively seeking solutions to problems', is that this is a more prominent strategy to use during intense periods of stress such as lockdown. The lack of association between problem focused coping reduces poor psychological outcomes in adults (for a review, see Penley et al., 2002) and might suggest that problem focused coping is not related to poor psychological outcomes in caregiver groups specifically. Caregivers in the current study seem to only use problem focused coping as a strategy during intense and stressful periods and that this strategy did not associate with their distress. More research is needed to further explore which coping strategies are used by different participant groups and how these strategies impact distress and wellbeing.

4.1 Limitations

This study had some limitations. Firstly, the current study relied on caregiver-reported diagnoses and behaviours which may have caused some bias in reporting; although, previous research has indicated that parent-reports are relatively reliable and robust (Rosenberg et al., 2009). Secondly, in the intellectual disabilities group, there was a range of developmental diagnoses, meaning different child characteristics could have influenced the intensity of child behaviours to which caregivers were exposed (McClintock et al., 2003) ultimately impacting psychological distress outcomes. Therefore, future studies should examine differential pathways exist relative to specific diagnoses. Finally as noted earlier, different sample sizes took part in T1 and T2 (not all participants took part in T2). This means that caution must be taken when comparing results between the two timepoints.

4.2 Conclusions

Despite these limitations the current study offers an insight into behaviours that challenge in children with and without intellectual disability and their caregivers' mental health during the COVID-19 lockdown at different time points in the UK. The study shows that both child

behaviours and caregiver psychological distress reduced as lockdown ended, however, caregivers' coping strategies may have contributed to increased mental health symptoms. These coping behaviours could be targeted during times of stress to reduce poor mental health outcomes, therefore this has considerable implications on interventions and support for caregiver groups.

5. References

Allerton, L. A., Welch, V., & Emerson, E. (2011). Health inequalities experienced by children and young people with intellectual disabilities: A review of literature from the United Kingdom. *Journal of Intellectual Disabilities, 15*(4), 269–278. <u>https://journals.sagepub.com/doi/10.1177/1744629511430772</u>

Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological assessment, 10(2),* 176. https://psycnet.apa.org/fulltext/1998-02891-012.pdf

Bailey, T., Hastings, R. P., & Totsika, V. (2021). COVID-19 impact on psychological outcomes of parents, siblings and children with intellectual disability: longitudinal before and during lockdown design. *Journal of Intellectual Disability Research, 65*(5), 397-404. <u>https://onlinelibrary.wiley.com/doi/pdfdirect/10.1111/jir.12818</u>

Baker, C., Kirk-Wade, E., Brown, J., & Barber, S. (2021). Coronavirus: A history of English lockdown laws. <u>https://commonslibrary.parliament.uk/research-briefings/cbp-9068/</u>

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47,* 217–230. <u>https://onlinelibrary.wiley.com/doi/pdf/10.1046/j.1365-2788.2003.00484.x</u>

BBC News (2022). Scotland to life most remaining Covid restrictions. Scotland, UK. <u>https://www.bbc.co.uk/news/uk-scotland-60042339</u>

BBC News (2022). COVID-19: Remaining restrictions in NI are lifted. Northern Ireland, UK. <u>https://www.bbc.co.uk/news/uk-northern-ireland-60381377</u>

Beach, S. R., Schulz, R., Donovan, H., & Rosland, A. M. (2021). Family caregiving during the COVID-19 pandemic. The gerontologist, 61(5), 650-660. <u>https://doi.org/10.1093/geront/gnab049</u>

Beaufort, I. N., De Weert-Van Oene, G. H., Buwalda, V. A., de Leeuw, J. R. J., & Goudriaan, A.
E. (2017). The depression, anxiety and stress scale (DASS-21) as a screener for depression in substance use disorder inpatients: a pilot study. *European Addiction Research, 23*(5), 260-268. <u>https://karger.com/ear/article/23/5/260/119698/The-Depression-Anxiety-and-Stress-Scale-DASS-21-as</u>

Benson, B. A., & Brooks, W. T. (2008). Aggressive challenging behaviour and intellectual disability. *Current Opinion in Psychiatry*, *21*(5), 454-458. <u>https://journals.lww.com/co-psychiatry/Fulltext/2008/09000/Stressful life events and physical health.6.aspx</u>

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual*

Disability Research, 50(3), 184-198. <u>https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1365-</u> 2788.2005.00768.x

Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical psychology, 62*(1), 17. https://psycnet.apa.org/fulltext/1994-25989-001.pdf

Cabinet Office (2020). Staying at home and away from others (social distancing). UK Government. <u>https://www.gov.uk/government/publications/full-guidance-on-staying-at-home-and-away-from-others</u>

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief cope. *International Journal of Behavioral Medicine,* 4(1), 92. <u>https://link.springer.com/content/pdf/10.1207/s15327558ijbm0401_6.pdf</u>

Chen, C. Y., Chen, I. H., Pakpour, A. H., Lin, C. Y., & Griffiths, M. D. (2021). Internet-related behaviors and psychological distress among schoolchildren during the COVID-19 school hiatus. *Cyberpsychology, Behavior, and Social Networking, 24*(10), 654-663. <u>https://www.liebertpub.com/doi/pdf/10.1089/cyber.2020.0497</u>

Clara, I. P., Cox, B. J., & Enns, M. W. (2001). Confirmatory factor analysis of the Depression– Anxiety–Stress Scales in depressed and anxious patients. *Journal of psychopathology and behavioral* assessment, 23, 61-67. <u>https://link.springer.com/content/pdf/10.1023/A:1011095624717.pdf</u>

Courtenay, K., & Perera, B. (2020). COVID-19 and People with Intellectual Disability: impacts of a pandemic. *Irish Journal of Psychological Medicine*, 1-21. <u>https://doi.org/10.1017/ipm.2020.45</u>

COVID-19: Remaining restrictions in NI are lifted. (2022). BBC News. https://www.bbc.co.uk/news/uk-northern-ireland-60381377

Cramm, J. M., & Nieboer, A. P. (2011). Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor. *Journal of Intellectual Disabilities*, 15(2), 101-113. <u>https://doi.org/10.1177/1744629511410922</u>

Culbertson, A. (2022). COVID-19: Wales set to life final remaining coronavirus restrictions. Sky News. <u>https://news.sky.com/story/COVID-19-wales-set-to-lift-final-remaining-</u> <u>coronavirus-restrictions-12622162</u>

Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. *Research in Developmental Disabilities*, 107, 103790. <u>https://doi.org/10.1016/j.ridd.2020.103790</u>

Dias, C., Cruz, J. F., and Fonseca, A. M. (2012). The relationship between multidimensional competitive anxiety, cognitive threat appraisal, and coping strategies: A multi-sport study. *International Journal of Sport and Exercise Psychology, 10,* 52–65. <u>https://www.tandfonline.com/doi/pdf/10.1080/1612197X.2012.645131?needAccess=true& role=button</u>

Diaz, A., Baweja, R., Bonatakis, J. K., & Baweja, R. (2021). Global health disparities in vulnerable populations of psychiatric patients during the COVID-19 pandemic. *World Journal of Psychiatry*, *11*(4), 94. <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8040151/</u>

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*(1), 39-52. <u>https://doi.org/10.1023/a:1026592305436</u>

Emerson, Eric, & Einfeld, S. (2010). Emotional and behavioural difficulties in young children with and without developmental delay: a bi-national perspective. *Journal of Child Psychology and Psychiatry*, *51*(5), 583–593. <u>https://doi.org/https://doi.org/10.1111/j.1469-7610.2009.02179.x</u>

Einfeld, S. L., Tonge, B. J., & Florio, T. (1994). Behavioural and emotional disturbance in fragile X syndrome. *American journal of medical genetics*, *51*(4), 386-391. <u>https://onlinelibrary.wiley.com/doi/pdf/10.1002/ajmg.1320510417</u>

Einfeld, S. L., & Tonge, B. J. (1995). The Developmental Behavior Checklist: The development and validation of an instrument to assess behavioral and emotional disturbance in children and adolescents with mental retardation. *Journal of autism and developmental disorders*, 25(2), 81-104. <u>https://link.springer.com/content/pdf/10.1007/BF02178498.pdf</u>

Ferguson, D., Brown, J., & Barber, S. (2021). Coronavirus: the lockdown laws - House of Commons Library. <u>https://commonslibrary.parliament.uk/research-briefings/cbp-8875/</u>

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school- age children with disabilities and behavior problems. *Family Relations, 46*, 359–371. <u>https://doi.org/10.2307/585096</u>

Fluharty, M., Bu, F., Steptoe, A., & Fancourt, D. (2021). Coping strategies and mental health trajectories during the first 21 weeks of COVID-19 lockdown in the United Kingdom. *Social*

Science & Medicine, 279, 113958. https://www.sciencedirect.com/science/article/pii/S0277953621002902

Folkman S. & Lazarus R. S. (1980) An analysis of coping in a middle-aged community sample.JournalofHealthandSocialBehavior21,219–39.https://www.jstor.org/stable/pdf/2136617.pdf

Fussell, E., & Lowe, S. R. (2014). The impact of housing displacement on the mental health of low-income parents after Hurricane Katrina. Social Science & Medicine, 113, 137-144. <u>https://doi.org/10.1016/j.socscimed.2014.05.025</u>

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. <u>https://doi.org/10.1093/jpepsy/jsn040</u>

Gallagher, S., & Wetherell, M. A. (2020). Risk of depression in family caregivers: unintended consequence of COVID-19. *BJPsych open*, 6(6), e119. <u>https://www.cambridge.org/core/services/aop-cambridge-core/content/view/65EAC3BD84DAE8EDE57701E169BE92A9/S205647242000099Xa.pdf/risk</u> of depression in family caregivers unintended consequence of covid19.pdf

Ganjiwale, D., Ganjiwale, J., Sharma, B., & Mishra, B. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *Journal of Family Medicine and Primary Care*, 5(2), 343. <u>https://doi.org/10.4103/2249-4863.192360</u>

Gillespie-Smith, K., McConachie, D., Ballantyne, C., Auyeung, B., & Goodall, K. (2021). The Impact of COVID-19 Restrictions on Psychological Distress in Family Caregivers of Children with Neurodevelopmental Disability in the UK. *Journal of Autism and Developmental Disorders*, 0123456789. <u>https://doi.org/10.1007/s10803-021-05132-3</u>

Gloster, A. T., Rhoades, H. M., Novy, D., Klotsche, J., Senior, A., Kunik, M., ... & Stanley, M. A. (2008). Psychometric properties of the Depression Anxiety and Stress Scale-21 in older primary care patients. *Journal of Affective Disorders, 110*(3), 248-259. <u>https://www.sciencedirect.com/science/article/pii/S0165032708000621</u>

Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positiveperceptions in mothers of children with intellectual disabilities. Journal of Applied ResearchinIntellectualDisabilities,15(3),269-275.https://onlinelibrary.wiley.com/doi/pdf/10.1046/j.1468-3148.2002.00104.x

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9(4), 377-391. <u>https://journals.sagepub.com/doi/pdf/10.1177/1362361305056078</u>

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, *50*(12), 874-882. https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1365-2788.2006.00904.x

lovino, E. A., Caemmerer, J., & Chafouleas, S. M. (2021). Psychological distress and burden among family caregivers of children with and without developmental disabilities six months into the COVID-19 pandemic. Research in Developmental Disabilities, 114, 103983. https://www.sciencedirect.com/science/article/pii/S0891422221001323

Isa, S. N. I., Ishak, I., Ab Rahman, A., Saat, N. Z. M., Din, N. C., Lubis, S. H., & Ismail, M. F. M. (2017). Perceived stress and coping styles among Malay caregivers of children with learning disabilities in Kelantan. *The Malaysian journal of medical sciences: MJMS, 24*(1), 81. <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5346006/</u>

Johnson, M. S., Skjerdingstad, N., Ebrahimi, O. V., Hoffart, A., & Johnson, S. U. (2022). Parenting in a Pandemic: Parental stress, anxiety and depression among parents during the government-initiated physical distancing measures following the first wave of COVID-19. *Stress and Health, 38*(4), 637-652. <u>https://europepmc.org/article/med/34902219</u>

Lancaster, R. L., Balling, K., Hastings, R., & Lloyd, T. J. (2014). Attributions, criticism and warmth in mothers of children with intellectual disability and challenging behaviour: a pilot study. *Journal of Intellectual Disability Research, 58*(11), 1060-1071. <u>https://onlinelibrary.wiley.com/doi/pdf/10.1111/jir.12029</u>

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* Springer publishing company.

Lee, L. C., Harrington, R. A., Chang, J. J., & Conners, S. L. (2008). Increased risk of injury in children with developmental disabilities. *Research in Developmental Disabilities*, 29, 247–255. https://www.sciencedirect.com/science/article/pii/S0891422207000431

Linehan, C., Aranten-Bergman, T., Beadle-Brown, J., Bigby, C., Birkbeck, G., Bradley, V., ... & Tossebro, J. (2020). COVID-19 IDD: A global survey exploring the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers. *HRB Open Research*, 3(39). <u>https://kar.kent.ac.uk/81864/1/9521304b-a069-4016-b2bd-fd284ffd3f08 13077 - christine linehan.pdf</u>

Lloyd, T., & Hastings, R. P. (2008). Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research, 52*(1), 37-48. <u>https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1365-2788.2007.00974.x</u>

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy, 33,* 335–343.

Macdonald, O. F. (2011). Putting the Puzzle Together: Factors Related to Emotional Wellbeing in Parents of Children with Autism Spectrum Disorders [Outstanding Honors Theses]. <u>https://digitalcommons.usf.edu/honors_et/52/</u>

McClintock, K., Hall, S., & Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study. *Journal of Intellectual Disability Research*, 47(6), 405-416. <u>https://doi.org/10.1046/j.1365-2788.2003.00517.x</u>

McConnell, D., & Savage, A. (2015). Stress and resilience among families caring for children with intellectual disability: Expanding the research agenda. *Current developmental disorders reports*, *2*, 100-109. <u>https://doi.org/10.1007/s40474-015-0040-z</u>

McGill, O. (2020). Challenging behaviour (ists): neurodiverse culture and applied behaviour analysis.

https://strathprints.strath.ac.uk/74248/3/McGill Pavilion 2020 neurodiverse culture and _applied behaviour analysis.pdf

Mutluer, T., Doenyas, C., & Genc, H. A. (2020). Behavioral Implications of the COVID-19 Process for Autism Spectrum Disorder, and Individuals' Comprehension of and Reactions to

thePandemicConditions.Frontiersinpsychiatry,11.https://www.frontiersin.org/articles/10.3389/fpsyt.2020.561882/full

Myrbakk, E., & Von Tetzchner, S. (2008). The prevalence of behavior problems among people with intellectual disability living in community settings. *Journal of Mental Health Research in Intellectual Disabilities,* 1(3), 205-222. <u>https://www.tandfonline.com/doi/pdf/10.1080/19315860802115607</u>

Neece, C., McIntyre, L. L., & Fenning, R. (2020). Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. *Journal of Intellectual Disability Research, 64*(10), 739-749. https://doi.org/10.1080/19315860802115607

National Institute for Health and Care Excellence, NICE (2015). Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilites whose behaviour challenges. <u>https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-1837266392005</u>

O'Connor, T. G. (2002). Annotation: The'effects'of parenting reconsidered: findings, challenges, and applications. Journal of Child Psychology and Psychiatry, 43(2), 555 - 572. doi:10.1111/1469-7610.00046.

Ó Donnchadha, S. (2018). Stress in caregivers of individuals with intellectual or developmental disabilities: A systematic review of mindfulness-based interventions. *Journal of Applied Research in Intellectual Disabilities, 31*(2), 181-192. <u>https://onlinelibrary.wiley.com/doi/pdf/10.1111/jar.12398</u>

O'Hagan, B. and Kingdom, S. (2020), Experiences of children with special educational needs and disabilities and their families in the United Kingdom during the coronavirus pandemic. *Tizard Learning Disability Review, 25, 4, 229-235.* <u>https://www.emerald.com/insight/content/doi/10.1108/TLDR-09-2020-0025/full/html</u>

Painter, J., Hastings, R., Ingham, B., Trevithick, L., & Roy, A. (2018). Associations between mental health problems and challenging behaviour in adults with intellectual disabilities: A test of the behavioural equivalents hypothesis. *Journal of Mental Health Research in Intellectual Disabilities, 104*, 1-16. <u>https://doi.org/10.1080/19315864.2018.1431747</u>

Panicker, A. S., & Ramesh, S. (2019). Psychological status and coping styles of caregivers of individuals with intellectual disability and psychiatric illness. *Journal of Applied Research in Intellectual Disabilities*, *32*(1), 1-14. <u>https://doi.org/10.1111/jar.12496</u>

Penley, J. A., Tomaka, J., & Wiebe, J. S. (2002). The association of coping to physical and psychological health outcomes: A meta-analytic review. *Journal of behavioral medicine, 25,* 551-603. <u>https://web.p.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=0&sid=9e3ce269-6f16-4860-94ac-2fae0087360d%40redis</u>

Petrocchi, S., Levante, A., Bianco, F., Castelli, I., & Lecciso, F. (2020). Maternal distress/coping and children's adaptive behaviors during the COVID-19 lockdown: mediation through children's emotional experience. *Frontiers in public health, 8,* 587833. <u>https://www.frontiersin.org/articles/10.3389/fpubh.2020.587833/full</u>

Poulus, D., Coulter, T. J., Trotter, M. G., & Polman, R. (2020). Stress and coping in esports and the influence of mental toughness. *Frontiers in psychology*, 11, 628. <u>https://www.frontiersin.org/articles/10.3389/fpsyg.2020.00628/full</u>

Russell, B. S., Hutchison, M., Tambling, R., Tomkunas, A. J., & Horton, A. L. (2020). Initial challenges of caregiving during COVID-19: Caregiver burden, mental health, and the parent–

child relationship. *Child Psychiatry* & *Human Development*, *51*, 671-682. https://link.springer.com/article/10.1007/s10578-020-01037-x

Senedd Research. (2022). Coronavirus timeline: Welsh and UK governments' response. Welsh Parliament. <u>https://research.senedd.wales/research-articles/coronavirus-timeline-welsh-and-uk-governments-response/</u>

Sherman, B. R. (1995). Impact of home-based respite care on families of children with chronic illnesses. Children's Health Care, 24(1), 33–45.

Sideropoulos, V., Dukes, D., Hanley, M., Palikara, O., Rhodes, S., Riby, D., ... Van Herwegen, J. (2021). The impact of COVID-19 on anxiety and wellbeing for families of individuals with Special Education Needs and Disabilities in the UK. Journal of Autism and Developmental Disorders. https://doi.org/10.31234/osf.io/gyhd9

Smith L. E., Seltzer M. M., Tager-Flusberg H., Greenberg J. S. & Carter A. S. (2008) A comparative analysis of wellbeing and coping among mothers of toddlers and mothers of adolescents with ASD. Journal of Autism and Developmental Disorders 38, 876–89. https://doi.org/10.1007/s10803-007-0461-6

Snowdon, A. W., Cameron, S., & Dunham, K. (1994). Relationships between stress, coping resources, and satisfaction with family functioning in families of children with disabilities. Canadian Journal of Nursing Research Archive, 63-76.

SPICe Spotlight. (2022). Timeline of Coronavirus (COVID-19) in Scotland. Health, Parliament & Government. https://spice-spotlight.scot/2022/06/30/timeline-of-coronavirus-COVID-19-in-scotland/

Taffe, J. R., Gray, K. M., Einfeld, S. L., Dekker, M. C., Koot, H. M., Emerson, E., ... & Tonge, B. J.(2007). Short form of the developmental behaviour checklist. American Journal on MentalRetardation,112(1),31-39.https://doi.org/10.1352/0895-

Tevis, C., & Matson, J. L. (2022). Challenging behaviour in children with developmental disabilities: an overview of behavioural assessment and treatment methods. *BJPsych Advances*, 1-9. <u>https://doi.org/10.1192/bja.2022.59</u>

Totsika, V., Hastings, R. P., Emerson, E., & Hatton, C. (2020). Early years parenting mediates early adversity effects on problem behaviors in intellectual disability. *Child Development*, *91*(3), e649-e664. DOI: 10.1111/cdev.13273

Unwin, G., & Deb, S. (2011). Family caregiver uplift and burden: Associations with aggressive behavior in adults with intellectual disability. Journal of Mental Health Research in Intellectual Disabilities, 4(3), 186-205. https://doi.org/10.1080/19315864.2011.600511

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, 115–130. https://doi.org/10.1177/1362361302006001009

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 17, 181–190. https://doi.org/10.1111/j.1468-3148.2004.00197.x

Willner, P., Rose, J., Stenfert Kroese, B., Murphy, G. H., Langdon, P. E., Clifford, C., ... & 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.

Zayac, R. M., & Johnston, J. M. (2008). Contriving establishing operations: Responses of individuals with developmental disabilities during a learning task. Research in Developmental Disabilities, 29, 202–216. https://doi.org/10.1016/j.ridd.2007.03.001

What's known

Research to date has reported that at one time point, COVID-19 impacted caregiver psychological distress <u>or</u> child behaviours that challenge in families who have children with Intellectual Disabilities (ID).

What's new

Given the bidirectional nature of child behaviour, caregiver coping and mental health, looking at these within the same participant group at more than one time point during COVID-19 is crucial to understand the processes that leads to caregiver psychological distress.

What's relevant

The current study showed that caregivers' coping strategies impacted psychological distress at both time points during COVID-19. This indicates that caregiver coping should be targeted for support and intervention to improve mental health outcomes.

Table 1

Sociodemographic characteristics as a percentage of the groups with vs without Intellectual Disabilities (ID), and variable means at Time Period 1 and Time Period 2.

	Т	1	Τ2	
	With ID	Without ID	With ID	Without ID
	(n = 90)	(n = 81)	(n = 58)	(n = 51)
Characteristic	N (%)	N (%)	N (%)	N (%)
Child's Age				
5 - 7	19 (21.1)	16 (19.8)	4 (6.9)	13 (25.5)
8 - 10	25 (27.8)	18 (22.2)	17 (29.3)	11 (21.6)
11 - 13	13 (14.4)	16 (19.8)	17 (29.3)	10 (19.6)
14 - 16	20 (22.2)	16 (19.8)	8 (13.8)	10 (19.6)
17 - 19	6 (6.7)	6 (7.4)	11 (19.0)	6 (11.8)
Did not disclose	7 (7.8)	9 (11.1)	1 (1.7)	0 (0.0)
Child's Gender				
Male	60 (66.7)	45 (55.6)	37 (63.8)	29 (56.9)
Female	29 (32.2)	35 (43.2)	21 (36.2)	21 (41.2)
Non-binary	1 (1.1)	1 (1.2)	0 (0.0)	1 (2.0)
Number of Siblings				
0	23	19 (23.5)	12 (20.7)	10 (19.6)
1	35	39 (48.1)	23 (39.7)	24 (47.1)
2	20	19 (23.5)	15 (25.9)	15 (29.4)
3	7	2 (2.5)	4 (6.9)	2 (3.9)
4	2	2 (2.5)	1 (1.7)	0 (0.0)
5+	2	0 (0.0)	2 (3.4)	0 (0.0)
Did not disclose	1	0 (0.0)	1 (1.7)	0 (0.0)
Caregiver's Educational Level				
No formal qualification	2	0 (0.0)	1 (1.7)	0 (0.0)
School Leaving Certificate		13 (16.0)	6 (10.3)	6 (11.8)
(e.g GCSE or A levels,				
Highers, High School				
Diploma or Certificate)	10			
Further vocational training for		8 (9.9)	14 (24.1)	6 (11.8)
a specific industry	18			
		34 (42.0)	26 (44.8)	24 (47.1)
University degree or		. /		~ /
equivalent (e.g BSc, BA, etc.)	37			
Postgraduate university degree		23 (28.4)	9 (15.5)	14 (27.5)
or equivalent (e.g MA, MSc,				. /
PhD, DClin, etc.)	20			
Other	3	2 (2.5)	2 (3.5)	1 (2.0)
Did not disclose	0	1 (1.2)	0 (0.0)	0 (0.0)
Caregiver's Employment		. /		
Homemaker	19	12 (14.8)	14 (24.1)	8 (15.7)
Volunteer work	2	0 (0.0)	1 (1.7)	0 (0.0)
Part time paid employment	32	28 (34.6)	20 (34.5)	18 (35.3)
Full time paid employment	22	36 (44.4)	15 (25.9)	21 (41.2)
Unemployed	2	0 (0.0)	1 (1.7)	0 (0.0)
Student	3	1 (1.2)	1 (1.7)	1 (2.0)
Other	10	4 (4.9)	6 (10.3)	3 (5.9)
Variable Means (sd)			· - /	

Child Behaviours that Challenge	6.661 (.708)	5.795 (.710)	4.391 (1.075)	3.073 (1.269)
Problem Focused Coping	4.383 (.558)	4.420 (.562)	4.165 (.578)	4.071 (.691)
Avoidant Coping	3.799 (.442)	3.638 (.533)	3.757 (.484)	3.649 (.444)
Emotion Focused Coping	5.053 (.546)	5.011 (.587)	5.084 (.557)	5.112 (.519)
Caregiver Stress	4.215 (.659)	3.842 (.604)	3.053 (1.136)	2.676 (1.037)
Caregiver Anxiety	3.654 (.673)	3.258 (.575)	2.231 (1.258)	1.763 (1.237)
Caregiver Depression	3.839 (.706)	3.509 (.633)	2.612 (1.179)	2.189 (1.154)

Figure Legend: Table shows the demographic percentages of the two groups (caregivers of neurotypical children and caregivers of children with Intellectual Disability) during Time Period 1 (T1; August-December 2021, n = 171); Time Period 2 (T2; January-March 2022, n = 109) and the variable means at Time Period 1 and Time Period 2.

Table 2:

Diagnosis as a percentage of the group with Intellectual Disability at T1 and T2

	T1 n = 90		T2 n = 58	
Diagnosis	Number	Percentage	Number	Percentage
Autism	28	31.1	17	29.3
Autism & ADHD or Developmental Delay	10	11.1	9	15.5
ADHD	3	3.3	3	5.2
Down Syndrome	11	12.2	8	13.8
Williams Syndrome	11	12.2	8	13.8
Intellectual Disability	10	11.1	5	8.6
Global/Developmental Delay	4	4.4	3	5.2
Williams Syndrome and Autism	1	1.1	1	1.7
Rare Chromosome Abnormality	2	2.2	2	3.4
Fragile X Syndrome	2	2.2	1	1.7
Coffin Siris Syndrome & Autism	1	1.1	-	-
Down Syndrome & Autism	2	2.2	1	1.7
Rubinstein-Taybi Syndrome & Autism	1	1.1	-	-
Cornelia de Lange Syndrome	4	4.4	-	-

Figure Legend: Table shows the diagnosis percentages of the group with Intellectual Disability during Time Period 1 (T1; August-December 2021, n = 171) and then again during Time Period 2 (T2; January-March 2022, n = 109).

	2. No. of siblings	3. Highest parent qualification	4. Parent marital status	5. Employ ment	6. T1 COPE Problem Focused	7. T1 COPE Avoidant	8. T1 COPE Emotion Focused	9. T1 Stress	10. T1 Anxiety	11. T1 Depression	12. T2 COPE Problem Focused	13. T2 COPE Avoidant	14. T2 COPE Emotion Focused	15. T2 Stress	16. T2 Anxiety	17. T2 Depression
1. Age in months	.056	036	066	020	.006	139	083	038	.010	034	046	151	044	100	.036	159
2. No. of siblings	-	191	.000	.004	030	.043	.007	.150	.131	.209*	.059	.102	.014	.184	.207	.211
3. Highest parent qualification		-	.101	.099	017	036	036	049	131	092	.000	060	186	186	251*	133
4. Parent marital status			_	020	.138	054	.017	.026	036	016	.103	.163	.113	089	.004	019
5. Employment				-	.068	070	008	049	008	078	030	.007	013	115	052	077

Table 3: Pearson's correlations between caregiver demographics, coping strategies and psychological distress at Time period 1 (T1) and Time period 2 (T2).

Table 4

Hierarchical Regression Summary: Caregiver Stress, Anxiety and Depression at Time 1

		В	95% CI		SE B	β	R ²	(Δ) R ²
Outcome	Variable		LL	UL				
Caregiver	Step1							
Stress	Constant	3.59	3.26	3.92	0.17			
	Group	0.28	0.08	0.49	0.10	0.21	0.04	0.04
	Step 2							
	Constant	1.80	1.07	2.54	0.37			
	Group	0.01	-2.09	0.22	0.11	0.01		
	DBC	0.35	0.22	0.48	0.07	0.42	0.18	0.14
	Step 3 for							
	AC							
	Constant	0.77	-0.00	1.55	0.39			
	Group	0.10	-0.10	0.30	0.10	0.73		
	DBC	0.17	0.03	0.31	0.07	0.21		
	AC	0.54	0.34	0.73	0.10	0.40	0.30	0.12
	Step 3 for							
	EFC							
	Constant	1.34	0.60	2.08	0.37			
	Group	0.03	-0.18	0.24	0.11	0.02		
	DBC	0.28	0.14	0.41	0.07	0.33		
	EFC	0.04	0.02	0.05	0.01	0.04	0.25	0.07
Caregiver	Step1							
Anxiety	Constant	3.08	2.76	3.41	0.16			
	Group	0.26	0.06	0.47	0.10	0.20	0.04	0.04
	Step 2							
	Constant	0.88	0.18	1.57	0.35			
	Group	-0.08	-0.28	0.13	0.10	-0.06		
	DBC	0.43	0.31	0.56	0.06	0.52	0.25	0.21
	Step 3							
	for AC							
	Constant	-0.20	-0.92	0.52	0.36			
	Group	0.02	-0.16	0.21	0.10	0.17		
	DBC	0.24	0.12	0.37	0.06	0.30		
	AC	0.56	0.38	0.75	0.09	0.42	0.39	0.14
	Step 3							
	for EFC							
	Constant	0.64	-0.84	1.36	0.37			
	Group	-0.06	-0.27	0.14	0.10	-0.05		
	DBC	0.39	0.27	0.52	0.07	0.48		
	EFC	0.02	0.01	0.04	0.01	0.15	0.27	0.02
Caregiver	Step1							
Depression	Constant	3.37	3.03	3.72	0.18			

Group Step 2	0.23	0.02	0.45	0.11	0.16	0.03	0.03
, Constant	1.24	0.48	2.00	0.39			
Group	-0.10	-0.32	0.13	0.11	-0.07		
DBC	0.42	0.28	0.55	0.07	0.48	0.20	0.18
Step 3							
Constant	0.01	-0.77	0.79	0.39			
Group	0.02	-0.19	0.22	0.10	0.01		
DBC	0.20	0.07	0.34	0.07	0.23		
AC	0.64	0.45	0.84	0.10	0.46	0.36	0.16

Note: Cl + Confidence interval; LL = lower limit; IL = upper limit; DBC = Developmental Behaviour Checklist; AC = avoidant coping subscale; EFC = emotion focused coping subscale

Figure Legend: Hierarchical model was carried out, group was entered as a dichotomous variable at step 1, child behaviours that challenge (DBC scores) at step 2 and coping strategy – avoidant coping at step 3; or Emotion Focused coping at step 3 with caregiver stress, anxiety and depression as the outcomes.

Table 5

Hierarchical Regression Summary: Caregiver Stress, Anxiety and Depression at Time 2

		В	95%	6 CI	SE B	β	R ²	(Δ) R ²
Outcome	Variable		LL	UL		•		
Caregiver	Step1							
Stress	Constant	2.30	1.63	2.97	0.34			
	Group	0.38	-0.04	0.80	0.21	0.17	0.03	0.03
	Step 2							
	Constant	1.76	1.06	2.46	0.35			
	Group	-0.03	-0.48	0.43	0.23	-0.01		
	DBC	0.31	0.14	0.48	0.09	0.37	1.33	0.10
	Step 3 for							
	AC							
	Constant	-0.86	-2.45	0.73	0.80			
	Group	0.06	-0.37	0.50	0.22	0.03		
	DBC	0.17	-0.01	0.35	0.09	0.21		
	AC	0.81	0.36	1.25	0.22	0.81	0.23	0.10
	Step 3 for							
	EFC							
	Constant	0.49	-0.63	1.61	0.57			
	Group	0.11	-0.34	0.56	0.23	0.05		
	DBC	0.21	0.03	0.39	0.09	0.26		
	EFC	0.05	0.16	0.09	0.02	0.27	0.20	0.06
Caregiver	Step1							
Anxiety	Constant	1.30	0.53	2.06	0.39			
	Group	0.47	-0.01	0.94	0.24	0.19	0.03	0.03
	Step 2							
	Constant	0.47	-0.29	1.24	0.39			
	Group	-0.15	-0.64	0.34	0.25	-0.06		
	DBC	0.47	0.28	0.65	0.09	0.50	0.22	0.19
	Step 3							
	for AC							
	Constant	-1.68	-3.46	0.09	0.90			
	Group	-0.08	-0.56	0.41	0.24	-0.03		
	DBC	0.36	0.16	0.56	0.10	0.38		
	AC	0.66	0.17	1.16	0.25	0.25	0.27	0.05
	Step 3							
	for EFC							
	Constant	-0.79	-2.02	0.44	0.62			
	Group	-0.01	-0.50	0.48	0.25	-0.01		
	DBC	0.37	0.18	0.57	0.10	0.40		
	EFC	0.05	0.01	0.10	0.02	0.23	0.27	0.05
Caregiver	Step1							
Depression	Constant	1.77	1.05	2.48	0.36			
1				-	·			

Group Step 2	0.42	-0.02	0.87	0.22	0.18	0.03	0.03
Constant	1.26	0.50	2.02	0.38			
Group	0.04	-0.45	0.53	0.25	0.02		
DBC	0.29	0.11	0.48	0.09	0.33	0.11	0.08
Step 3		-				-	
Constant	-2.05	-3.74	-0.37	0.85			
Group	0.15	-0.31	0.61	0.23	0.06		
DBC	0.12	-0.06	0.31	0.09	0.14		
AC	1.02	0.55	1.49	0.24	0.40	0.25	0.13

Note: Cl + Confidence interval; LL = lower limit; IL = upper limit; DBC = Developmental Behaviour Checklist; AC = avoidant coping subscale; EFC = Emotion Focused Coping

Figure Legend: Hierarchical model was carried out, group was entered as a dichotomous variable at step 1, child behaviours that challenge (DBC scores) at step 2 and coping strategy – avoidant coping and emotion focused coping at step 3 with caregiver stress, anxiety and depression as the outcomes.