

# **Research Project Portfolio**

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Mental Health and Clinical Neurosciences  
School of Medicine

## **Doctorate in Clinical Psychology**

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### **Adapting Compassionate Mind Training into Guided Self-Help for Parents of Autistic Children**

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Submitted in part fulfilment of the requirements for the

**Doctorate in Clinical Psychology**

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## Portfolio Abstract

**Background:** Parents of autistic children (PAC) are at increased risk of psychological distress, including parental stress, shame and self-criticism. Poor parental mental health can adversely affect parent-child interactions and their attachment relationship, in a transactional manner. There is a lack of evidence-based PAC-specific interventions focusing on reducing their psychological distress. Furthermore, PAC experience multiple barriers to accessing direct psychological interventions provided by health services. Compassion Focused Therapy (CFT) is a recommended transdiagnostic intervention for high shame and self-criticism and is potentially applicable for use as preventative guided self-help with PAC. Cross-sectional research has shown that increased PAC self-compassion is associated with increased well-being and reduced psychological distress. There is limited research around the use of CFT with PAC. No PAC-specific CFT self-help resources are available.

**Study aims:** To explore adaptations needed to use a CFT resource as a guided self-help intervention with PAC, and to define anticipated factors influencing successful intervention implementation during future feasibility testing.

### Research questions:

- How can a CFT resource be adapted into a guided self-help intervention for PAC, whilst maintaining theoretical coherence, for further investigation during feasibility testing?
- What are stakeholder views regarding anticipated factors influencing successful implementation of the CFT resource during future feasibility testing?

**Methods:** Abiding by practice guidelines for intervention adaptation, five iterative phases of stakeholder feedback on an existing CFT resource for parents were facilitated, leading to subsequent intervention refinement. Phases one and two involved focus groups with PAC. Phases three and four involved seeking written commentary and a later focus group with clinical psychologists (CPs) working within children's autism services. The fifth phase involved seeking written commentary from all

participants that had opted into receiving updates about the project and CFT experts. Directed Content Analysis supported extraction of adaptation suggestions during each feedback round. A secondary Framework Analysis was later employed to all focus group data to meet the second research aim.

**Results:** Compassionate Mind Training for Parents of Autistic Children (CMT-PAC) guided self-help intervention was developed. Seven PAC, four CPs and one CFT expert provided feedback on CMT-PAC which led to adaptations. CFT-trained clinicians deemed the final CMT-PAC maintained theoretical coherence. Two key concepts from the Framework Analysis were recognised in all focus groups: 'personal and social context of parents' and 'barriers and facilitators to engagement'. Stakeholders raised several further research questions to consider when CMT-PAC undergoes feasibility testing.

**Discussion:** This study is the first to adapt a CFT intervention for PAC in collaboration with multiple stakeholder groups. Stakeholders anticipated CMT-PAC will be valuable for PAC and services, and highlighted key facilitators for successful implementation, including cultivating a therapeutic relationship via modelling compassionate qualities within the text, and promoting flexible intervention engagement. Potential issues requiring further consideration were highlighted, such as whether fears of compassion may reduce engagement in self-directed practices, and queries around feasibility of imagery and body-based CMT exercises due to PAC differences associated with neurodivergence. Future research should involve studies of CMT-PAC to investigate the acceptability, feasibility and effectiveness in cultivating compassion and reducing psychological distress among PAC.



## **Statement of Contribution**

Francesca Kemp was responsible for project design, ethical application, literature review, participant recruitment, data collection, data analysis, intervention adaptation, and the write up of the research.

Dr Mark Hudson and Professor Thomas Schröder provided support as research supervisors around the study design, ethical application, data analysis, intervention adaptation and write up.

Dr Corinne Gale provided support during intervention adaptation and assisted with the facilitation of data collection during parent focus groups by making observational notes.

Heather Woodman (Trainee Clinical Psychologist) provided brief support during the quality assessment for the directed content analysis.

## **Journal Paper**

Formatted in preparation for submission to the 'Psychology and Psychotherapy:  
Theory, Research and Practice' (*See Appendix A for journal submission guidelines*).


**Title: Adapting Compassionate Mind Training into Guided Self-Help for Parents  
of Autistic Children**

*Short title: Compassion for Autistic Childs' Parents*

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**Abstract**

**Objectives:** Parents of autistic children (PAC) are at increased risk of psychological distress, including shame and self-criticism. Compassion Focused Therapy (CFT) is a recommended transdiagnostic intervention for such difficulties, but to date there is limited research around the use of CFT with PAC. The present study aimed to explore the adaptations needed for a guided self-help CFT intervention for wellbeing, and the potential factors influencing future implementation during feasibility testing, through engagement with relevant stakeholders.

**Design:** A two-stage qualitative research design aimed to (1) extract and configure stakeholder feedback for adaptations and (2) understand stakeholder views regarding

the anticipated factors influencing implementation of the CFT resource during future feasibility testing.

**Methods:** Five iterative rounds of stakeholder feedback and intervention refinement were facilitated, using focus groups and written commentary with PAC ( $n=7$ ), clinical psychologists working within children's autism services ( $n=4$ ), and a CFT expert ( $n=1$ ). Directed Content Analysis supported extraction of adaptation suggestions during each feedback round. Framework Analysis was employed to all focus group data to meet the second research aim.

**Results:** *Compassionate Mind Training for Parents of Autistic Children* (CMT-PAC) guided self-help intervention was developed. Two key concepts from the Framework Analysis were recognised across focus groups: 'personal and social context of parents' and 'barriers and facilitators to engagement'.

**Conclusions:** Stakeholders appeared optimistic about the use of CMT-PAC within a future feasibility study. However, some potential issues were raised relating to how CMT-PAC could be implemented amongst the target population. Implications for research and clinical practice are discussed.

### **Keywords**

Compassion, Parents, Autism, Adaptation, Intervention, Acceptability.

### **Data availability statement**

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## **Acknowledgements**

Thanks to Dr James Kirby for providing permission to use and adapt a Compassionate Mind Training workbook for parents within this study.

This study was funded by Health Education England and conducted in partial fulfilment of the first author's Doctorate in Clinical Psychology.

## **Practitioner Points**

- A compassion focused guided self-help intervention promoting flexible engagement options is endorsed as a potentially viable well-being intervention for parents of autistic children, by members from the target population and clinicians.
- Pre-assessment for compassion focused guided self-help intervention studies with parents of autistic children should involve considerations around fears of compassion as a potential barrier during self-directed practice. Techniques to reduce fear and resistance towards compassion within the guided self-help format require consideration.
- Many parents of autistic children may be neurodivergent, and stakeholders questioned whether potential associated learning needs could reduce capacity to experience imagery or body-based CMT exercises effectively. Further research regarding the effectiveness of this therapeutic approach with autistic adults is required.
- Stakeholders highlighted a need to cultivate a therapeutic relationship with the self-help materials through modelling of a compassionate stance within the text, to improve engagement.

## Introduction

Autism is a lifelong neurodevelopmental condition characterised by differences in communication, social interaction, and restricted, repetitive interests or behaviours (American Psychiatric Association, 2013)<sup>1</sup>. Estimated prevalence rates report 700,000 autistic people and a subsequent three million carers in the United Kingdom (Department of Health & Social Care & Department for Education, 2021; National Autistic Society, n. d.), comparable to the estimated 1% worldwide prevalence of autism (Zeidan et al., 2022). In reality, these figures may be doubled due to age-related diagnostic inequalities, as a possible 750,000 further undiagnosed autistic people are estimated within England alone (O’Nions et al., 2023).

## Parental Mental Health

Parenting an autistic child can be greatly rewarding, although may present unique challenges (Khan et al., 2016). A wealth of literature evidences the prevalence of psychological distress in parents of autistic children (PAC), including higher rates of depression, anxiety, stress, and lower quality of life (DesChamps et al., 2020; Hayes & Watson, 2013; Hsiao, 2016; Jellett et al., 2015; Lushin & O’Brien, 2016; Piro-Gambetti et al., 2023; Stewart et al., 2017; Weiss et al., 2012)<sup>2</sup>. Parents’ responses to their child’s diagnosis (Legg & Tickle, 2019; Rabba et al., 2019), management of child/ren’s differences associated with key features of autism, financial and familial pressures, and barriers to service support (Crane et al., 2016) are evidenced as risk factors associated with poorer parental mental health<sup>3</sup>.

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<sup>1</sup> see section 1.1 in extended for the definition of autism.

<sup>2</sup> See section 1.2 in extended for further discussion around parental mental health outcomes.

<sup>3</sup> See section 1.3 in extended for further discussion around factors influencing parental mental health.

Furthermore, autistic children are more likely to experience public stigma<sup>4</sup>, such as social exclusion and victimisation from their peers (Trundle et al., 2023) or blame for appearing disruptive (Swaab et al., 2023). Subsequently, parents often experience prejudice and discrimination due to their association with a publicly stigmatised person (Kinnear et al., 2016; Rusu et al., 2024), leading to internalisation from repeated exposure to these experiences, known as affiliate stigma (Deguchi et al., 2021; Milačić-Vidojević et al., 2014). Research indicates that PAC experience severe affiliate stigma (Liao et al., 2019; Salleh et al., 2020; Zhou et al., 2018) and subsequent shame<sup>5</sup> (Burrell et al., 2017; Papadopoulos et al., 2019; Rusu et al., 2024; Salleh et al., 2020). Shame is a universal socially-focused emotion arising from negative self-evaluation in relation to societal norms (Tangney et al., 2004; Wolf et al., 2010) and is linked to defensive strategies of inhibition (Gilbert, 2019). Shame is evidenced to mediate the relationship between individuals' adverse experiences, such as affiliate stigma, and onset and maintenance of parental mental health difficulties (Lewis, 2019).

Bidirectional effects incorporating poor parental mental health and child autism-related differences can inadvertently reduce quality parent-child interactions and their attachment relationship (Fanti et al., 2013; Neece et al., 2012). Rodriguez et al. (2019) evidenced that high parenting stress positively predicted child internalising behaviours, such as social withdrawal and low mood, and a reciprocal relationship was observed between parental stress and children's externalising behaviours, such as aggression and impulsivity. Poorer parental emotional regulation skills are associated with poorer child developmental outcomes, including their social and communication skills, ability to emotionally self-regulate, and empathy development (Crowell et al., 2019).

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<sup>4</sup> See section 1.4 in extended for further discussion around stigma and stigma theories.

<sup>5</sup> See section 1.5 in extended for further discussion around shame and shame theories.

## Treatment Options for Parental Mental Health

Despite reduced parental emotional regulation skills observed in PAC, there is little acknowledgement of parental mental health needs within current health-related policies, such as the National Autism Strategy (Department of Health & Social Care & Department for Education, 2021) and The NHS (2019) Long Term Plan. There are no specific guidelines for mental health treatment among PAC<sup>6</sup>. The National Institute for Health and Care Excellence (NICE; 2021b) recommend clinicians provide advice and emotional support to PAC, yet there is minimal research regarding systemic working with this population, and services are commissioned with greater focus on child needs (NHS England, n. d.), so parents are often missed (Griffin et al., 2024).

Research around PAC-specific mental health interventions is dominated by interventions targeting child 'problem' behaviours, and skills-based psychoeducational parenting programs (Bearss et al., 2015; Wyatt Kaminski et al., 2008)<sup>7</sup>. This trend is criticised for neglecting PAC psychological difficulties (Li et al., 2024). Systematic literature reviews for mental health interventions with PAC have highlighted the absence of quality research, where included studies indicated variable quality concerns, including high risk of bias and attrition (Catalano et al., 2018; Da Paz & Wallander, 2017; Juvin et al., 2022; Kulasinghe et al., 2023; Li et al., 2024; MacKenzie & Eack, 2022). Many lacked a conceptual framework or overall conceptual coherence, and only a small number of studies were found to use evidence-based interventions, including cognitive behaviour therapy (CBT), acceptance and commitment therapy, and mindfulness-based interventions.

Research indicates several barriers preventing PAC from seeking mental health support, including having limited knowledge of service accessibility, ambiguous service

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<sup>6</sup> See section 1.6 in extended for current policy and guidelines for the support of parents of autistic children.



pathways, familial financial pressures, service inflexibility, and stigma (Bonis, 2016; Braddock & Twyman, 2014; Nealy et al., 2012; Osborn et al., 2020; Wallace-Watkin et al., 2023). Structured in-person support is implied as inaccessible for many PAC, and it may be reasonable to assume that shame proneness may further deter PAC from accessing support (Dunford & Granger, 2017). Use of guided and unguided self-help<sup>8</sup> interventions are evidenced to help overcome practical and psychological barriers described above (Döpfner et al., 2021) and could provide greater scope for PAC to access timely and evidence-based psychological treatment.

### **Potential Benefits of Compassion**

Definitions of compassion<sup>9</sup> are grounded within Buddhist tradition, comprising of two core elements; motivation to engage with suffering, and actively engaging to alleviate, reduce or prevent further suffering in response (Gilbert, 2010; The Dalai Lama & Vreeland, 2001). Evolutionary theories suggest compassion as an antidote for shame, through enabling individuals to move from shame-related competitive motivational systems into a soothing motivational system, resulting in affiliative patterns of emotional disposition and self-to-self relating (Gilbert, 2019). Cross-sectional research<sup>10</sup> indicates that compassion is positively associated with greater wellbeing factors in PAC populations, including life satisfaction, quality of life, hope, and goal engagement, and it is negatively associated with parental stress, depression, guilt and shame in response to challenging parenting events, and distress arising from affiliate stigma (Bohadana et al., 2019; Neff & Faso, 2015; Sirois et al., 2019; Torbet et al., 2019; Wong et al., 2016). Greater compassion levels are also evidenced to predict more psychologically facilitative parenting styles (Kirby, Grzazek, et al., 2019) and

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<sup>8</sup> See section 1.7 in extended for further information regarding guided self-help interventions.

<sup>9</sup> See section 1.8 in extended for discussion regarding definitions of compassion.

<sup>10</sup> See section 1.9 in extended for further discussion around the influence of parental compassion for parents and their children.

greater warmth during parent-child interactions amid challenging parenting events (Miller et al., 2015).

Crucially, compassion is recognised as a modifiable trait (Neff & Germer, 2013) and has recently become a therapeutic intervention focus for a range of mental health difficulties, especially those attributed to shame and self-criticism, with growing empirical support (Kirby et al., 2017; Leaviss & Uttley, 2015). Many involve Compassionate Mind Training (CMT) exercises taken from Compassion Focused Therapy (CFT; Gilbert, 2009)<sup>11,12</sup>, which can be used as a standalone intervention to support individuals to cultivate compassion, to approach and alleviate distress (Gilbert & Procter, 2006; Irons & Heriot-Maitland, 2021). Considering the high prevalence of shame experienced by PAC, which is attributed to poorer mental health outcomes, compassion focused interventions could be a viable approach for this population as an alternative to other evidence-based psychological therapies, such as CBT.

Systematic reviews provide tentative evidence towards efficacy of compassion-based interventions used with parents to improve self-compassion, depression, anxiety and mindfulness (Jefferson et al., 2020; Kemp et al., 2022) although highlight variable methodological quality of included studies.<sup>13</sup> Kirby et al. (2023) since evidenced efficacy of brief CFT approaches with parents using a two-hour seminar and workbook. Findings demonstrated significant reductions in parental self-criticism and child emotional problems at two-weeks post-intervention, which were sustained at three-month follow up, alongside further positive changes observed in parenting styles. Brief interventions such as this hold promise, as they may be efficacious for enhancing PAC well-being and provide greater opportunities for flexible engagement in psychological support, which may mitigate some of the barriers to accessing help that are

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<sup>11</sup> See section 1.10 in extended for theory underpinning Compassion Focused Therapy.

<sup>12</sup> See section 1.11 in extended for further details regarding Compassionate Mind Training.

<sup>13</sup> See section 1.12 in extended for further details regarding the evidence base for compassion-based interventions.

experienced by this population. When the present research was proposed, only two studies of compassion-based interventions with PAC were published (Fernandez-Carriba et al., 2019; Rojas-Torres et al., 2021). Neither group interventions involved CFT but described promising findings relating to parental mental health outcomes. However, they were limited by low intervention uptake (Fernandez-Carriba et al., 2019), unclear reporting regarding intervention adaptation procedures, and compassion-related intervention components were ill-defined in the report (Rojas-Torres et al., 2021).<sup>14</sup>

### **Adapting Complex Psychological Interventions<sup>15</sup>**

Effectiveness of public health interventions rely on the quality of intervention design, which should occur before feasibility testing<sup>16</sup> or implementation trials are considered (Wight et al., 2016). The National Medical Council<sup>17</sup> (Skivington et al., 2021a, 2021b) and World Health Organization (2024) guidance advocates for stakeholder engagement to inform refinements that are anticipated to enhance acceptability, relevance and feasibility of interventions during future use.<sup>18</sup> The Adapting interventions to new contexts (ADAPT) guidance (Moore et al., 2021) and Model for Adaptation Design and Impact (MADI; Kirk et al., 2020) provide guidelines for systematic adaptation of evidence-based interventions, whilst considering impact on outcomes. There are calls for better reporting regarding patient and public involvement within intervention adaptation studies (O’Cathain et al., 2019). The Framework for

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<sup>14</sup> See section 1.13 in extended for detailed critique of studies of compassion-based interventions with parents of autistic children.

<sup>15</sup> See section 1.14 in extended for definition of complex interventions.

<sup>16</sup> See section 1.15 in extended for definition of feasibility studies within intervention research.

<sup>17</sup> See section 1.16 in extended for discussion around intervention adaptation frameworks and theories.

<sup>18</sup> See section 1.17 in extended for discussion around co-production of public mental health interventions.

Reporting Adaptations and Modifications (FRAME; Stirman et al., 2013, 2019) provides a standardised framework to support this.

## **Study Rationale<sup>19</sup>**

Studies of PAC-specific CFT interventions are warranted, to consider whether the approach could enhance psychological well-being among this population, and to advance the existing evidence base for this therapy modality. An existing CFT workbook for parents<sup>20</sup> (Kirby et al., 2023) was provided by the authors with permission<sup>21</sup> to adapt for use with PAC. This intervention would aim to primarily increase PAC self-compassion, which may positively influence a range of PAC and child well-being outcomes. Guided self-help interventions could hold value as a preventative well-being approach for PAC, who may face barriers when seeking psychological support. The adaptation process requires further exploration with relevant stakeholders.

## **Aims**

To explore adaptations needed to use a CFT resource as a guided self-help intervention with PAC, and to define anticipated factors influencing successful implementation during future feasibility testing.

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<sup>19</sup> See section 1.18 in extended for further rationale.

<sup>20</sup> See section 1.19 in extended for information about the original CFT workbook resource.

<sup>21</sup> See Appendix B for evidence of email permission received from Dr James Kirby.

## Research Questions

- How can a CFT resource be adapted into a guided self-help intervention for PAC, whilst maintaining theoretical coherence, for further investigation during feasibility testing?
- What are stakeholder views regarding anticipated factors influencing successful implementation of the CFT resource during future feasibility testing?

## Materials & Methods

A qualitative research design was undertaken from a pragmatist epistemological position<sup>22</sup>. The study received favourable ethical opinion<sup>23</sup> from the University of Nottingham Mental Health and Clinical Neurosciences ethics committee (reference: 3003).

## Participants

Participants involved PAC and Clinical Psychologists (CPs) within the United Kingdom. PAC were aged 18 or over, could communicate using English language, and had a child/ren aged under 18 years with a current diagnosis of autism. CPs were registered with the Health and Care Professions Council and were employed within children's autism services, thus regularly provided psychological support to PAC. All participants required technology to engage in virtual focus groups via Microsoft Teams. Written feedback from international CFT clinicians was later requested, who had expertise around the theoretical approach and its application with parents.<sup>24</sup>

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<sup>22</sup> See section 2.1 in extended for epistemological stance.

<sup>23</sup> See section 2.2 in extended for ethical considerations.

<sup>24</sup> See section 2.3 in extended for further details regarding CFT experts.

## Recruitment<sup>25</sup>

PAC were recruited via an advert circulated through social media and within regional and national parent support groups, autism charities, and organisations within the United Kingdom. Potential participants expressed their interest to the lead researcher via email and were sent a Focus Group Guidelines document with a Participant Information Sheet detailing ethical considerations. All were offered a screening meeting to provide opportunity to ask questions about the research. PAC were asked to complete a Consent Form to opt into the project.

CPs were recruited through professional networking and snowball sampling and experienced the same recruitment process as PAC. Alternative versions of the Participant Information Sheet and Consent Form were shared with CPs. CFT experts were contacted directly through email by the lead researcher.

## Procedure

Data were collected over five iterative rounds of stakeholder feedback and intervention refinement, based on the process model outlined in the ADAPT guidance (Moore et al., 2021).

**Phase One.** The existing CMT workbook was sent via email to PAC for review, alongside a demographic questionnaire. One week later, PAC participated in a ninety-minute audio-recorded virtual focus group meeting<sup>26,27</sup> moderated by the lead researcher. The field supervisor attended to record observations about group processes, including non-verbal indicators. PAC provided feedback on the workbook

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<sup>25</sup> See section 2.4 in extended for further details regarding study advertisement.

<sup>26</sup> See section 2.5 in extended for justification for focus groups and alternative methods considered.

<sup>27</sup> See section 2.6 in extended for development of interview schedules.

materials for future feasibility testing, and to share recommendations for further adaptation. Feedback influenced the nature of intervention refinement.

**Phase Two.** PAC were sent the updated CMT workbook and invited to a second audio-recorded ninety-minute virtual focus group with the same facilitators, to gain a majority agreement on changes made, and to gain further feedback and recommendations for adaptation. All were provided a debrief letter following the second focus group. The resource was subsequently refined.

**Phase Three.** The resource was sent to CPs alongside a demographic questionnaire, with request for written feedback within a four-week period. An email reminder was sent seven days before the feedback deadline. Written feedback was collated to inform further intervention refinements, and the updated resource was returned to CPs. Any conflicting feedback was noted and anonymised.

**Phase Four.** A subsequent two-hour audio-recorded virtual focus group was facilitated with all CPs, to gain a consensus view on each conflicting recommended adaptation, and for further discussion around perceived advantages and disadvantages of the proposed intervention, the applicability of CMT to PAC, and to obtain opinions regarding whether theoretical coherence was maintained following adaptation. The intervention was refined.

**Phase Five.** The resource was sent to international CFT experts via email for commentary around whether theoretical coherence was maintained following adaptation, and for their opinions regarding the applicability of CMT with PAC.<sup>28</sup> Participants who opted to receive research updates were emailed the updated resource with an optional invitation to provide final written comments.

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<sup>28</sup> See section 2.7 in extended for visual depiction of research procedure.

## Analysis<sup>29</sup>

**Extracting suggested amendments.** Focus group recordings were transcribed verbatim by the lead researcher. A rapid assessment for suggested amendments was facilitated following each stage of data collection using deductive directed content analysis<sup>30</sup> (DCA; Elo & Kyngäs, 2008) using a codebook developed from FRAME (Stirman et al., 2013, 2019). Transcripts and written feedback were searched for negative comments about the intervention and suggested amendments from participants. As context of information coded was relevant, thematic units were used rather than line-by-line coding, as this would have risked fragmenting amendment requests.

**Adaptation protocol.**<sup>31</sup> To uphold intervention fidelity throughout the adaptation process, the lead researcher reviewed the MADi model (Kirk et al., 2020) which proposes four possible mediating or moderating factors of intervention adaptation characteristics on potential outcomes. These were consulted to review appropriateness of each recommended adaptation. Where a consensus opinion could not be achieved within or between stakeholder groups, suggestions were discussed within the research team to determine appropriateness of implementing one or multiple conflicting requests, and a majority decision was sought.

**Categorising adaptation types.** A taxonomic analysis<sup>32</sup> (Holtrop et al., 2022) was performed to group goals and nature of intervention adaptations into clustered adaptation 'types'. This involved calculating frequencies for each adaptation component combination during each phase of refinement. This functioned to enhance

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<sup>29</sup> See section 2.8 in extended for justifications for analytic methods used and other methods considered.

<sup>30</sup> See section 2.9 in extended for directed content analysis process.

<sup>31</sup> See section 2.10 in extended for further details regarding the adaptation protocol.

<sup>32</sup> See section 2.11 in extended for details regarding the taxonomic analysis process.



reporting of reasons for adaptations and is hoped to enrich future investigations regarding intended and actual impact of adaptations during feasibility testing.

**Defining anticipated factors influencing successful implementation.** A framework analysis<sup>33</sup> (FA; Ritchie & Spencer, 1994) was employed to all focus group transcripts to define concepts relevant to the second research question that arose between stakeholder groups. FA was chosen as it is a flexible tool that is not associated with any epistemological paradigm and provides a systematic analytical approach for time-limited research objectives (Gale et al., 2013). FA enables the researcher to move between stages of raw data, abstraction, and interpretation, to foster transparency and replicability during data management and interpretative processes (Ritchie et al., 2014; Smith & Firth, 2011). The indexing process followed an inductive-deductive approach, where key themes were already developed through a *priori* knowledge that had influenced interview schedule development. However, data were coded inductively if it did not fit pre-determined codes yet appeared to answer the second research question, and so framework matrices were subsequently refined.

### **Quality considerations<sup>34</sup>**

The lead researcher used a reflexive log and research supervision to consider the influence of personal experiences and interpretations throughout the research process. During the FA indexing phase, the second author checked 20 percent of a coded transcript for plausibility of inductive coding. Charting and interpretation processes were discussed within supervision.

Inter-rater reliability assessments were conducted during the DCA, supported by an independent doctoral researcher. Twenty percent of a focus group transcript was

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<sup>33</sup> See section 2.12 in extended for framework analysis process.

<sup>34</sup> See section 2.13 in extended for further details regarding quality considerations.

separately coded by the doctoral researcher for presence or absence of a suggested adaptation per participant comment. Percentage agreement and Cohen's (1960, 1968) Kappa coefficients indicated substantial to excellent agreement (90.4% agreement,  $\kappa=0.79$ ; Landis & Koch, 1977). 20 percent of amendment suggestions across all phases were separately coded by both nature and goal for adaptation. A pooled Kappa estimator (De Vries et al., 2008) indicated excellent agreement between coder's judgements (97% agreement,  $\kappa_{pooled}=0.94$ ).

## Results

### *Participant Demographics*

Seven PAC and four CPs were recruited. All except one PAC provided demographic information, summarised in Table 1. Three PAC disclosed they were neurodivergent within the focus groups.

**Table 1**

#### *Sample Characteristics*

| <b>Factor</b>          | <b>Parents,<br/><i>n</i> (%)</b> | <b>Clinical<br/>Psychologists,<br/><i>n</i> (%)</b> |
|------------------------|----------------------------------|-----------------------------------------------------|
| <b>Age</b>             |                                  |                                                     |
| 20-29 years            | 1 (14.3)                         | 0 (0)                                               |
| 30-39 years            | 2 (28.6)                         | 1 (25)                                              |
| 40-49 years            | 2 (28.6)                         | 3 (75)                                              |
| 50-59 years            | 1 (14.3)                         | 0 (0)                                               |
| <b>Gender</b>          |                                  |                                                     |
| Female                 | 6 (85.7)                         | 4 (100)                                             |
| <b>Ethnicity</b>       |                                  |                                                     |
| Asian or Asian British | 1 (14.3)                         | 0 (0)                                               |
| Black or Black British | 1 (14.3)                         | 0 (0)                                               |
| White or White British | 4 (57.1)                         | 4 (100)                                             |

| <b>Factor</b>                                                                   | <b>Parents,<br/>n (%)</b> | <b>Clinical<br/>Psychologists,<br/>n (%)</b> |
|---------------------------------------------------------------------------------|---------------------------|----------------------------------------------|
| <b>Marital status <sup>a</sup></b>                                              |                           |                                              |
| Single                                                                          | 1 (14.3)                  | -                                            |
| Married/Civil Partner                                                           | 4 (57.1)                  | -                                            |
| Divorced/Partnership Dissolved                                                  | 1 (14.3)                  | -                                            |
| <b>Age of child <sup>a</sup></b>                                                |                           |                                              |
| Up to 5 years                                                                   | 1 (14.3)                  | -                                            |
| 6 to 10 years                                                                   | 2 (28.6)                  | -                                            |
| 11 to 15 years                                                                  | 2 (28.6)                  | -                                            |
| 15 to 17 years                                                                  | 1 (14.3)                  | -                                            |
| <b>Highest level of professional qualification <sup>b</sup></b>                 |                           |                                              |
| Doctorate in Clinical Psychology                                                | -                         | 3 (75)                                       |
| Post-Doctoral Training                                                          | -                         | 1 (25)                                       |
| <b>Compassion Focused Therapy trained? <sup>b</sup></b>                         |                           |                                              |
| Yes                                                                             | -                         | 4 (100)                                      |
| <b>Years' experience working with parent of autistic children? <sup>b</sup></b> |                           |                                              |
| 4 years                                                                         | -                         | 1 (25)                                       |
| 10 years                                                                        | -                         | 1 (25)                                       |
| 14 years                                                                        | -                         | 2 (50)                                       |

<sup>a</sup> Question for PAC only; <sup>b</sup> Question for CPs only.

### ***Intervention Adaptation***

Adaptation occurred iteratively over four phases. No amendments were suggested during phase five.<sup>35,36,37</sup> Three PAC attended focus group one (FG1) and a fourth did not attend due to technological difficulties, so provided brief written feedback. Five PAC attended focus group two (FG2), including two from FG1 and three new participants<sup>38</sup>. All CPs provided written feedback and attended focus group three (FG3), although one arrived late and thus did not contribute to all consensus-making

<sup>35</sup> See section 3.1 in extended for a narrative summary of each adaptation phase.

<sup>36</sup> See section 3.2 in extended for example feedback from parents.

<sup>37</sup> See section 3.3 in extended for example feedback from CPs.

<sup>38</sup> See section 3.4 in extended for an account of the subjective observations across focus groups from facilitators.

discussions. Table 2 provides an overview regarding the nature of adaptations made per feedback phase.<sup>39</sup>

**Table 2**

*Changes Made According to the FRAME Model by Phase*

| <b>Process</b>                                                      | <b>Phase</b> |   |   |   |
|---------------------------------------------------------------------|--------------|---|---|---|
|                                                                     | 1            | 2 | 3 | 4 |
| <b>When did modifications occur?</b>                                |              |   |   |   |
| Pre-implementation/planning/pilot                                   | X            | X | X | X |
| <b>Were adaptations planned?</b>                                    |              |   |   |   |
| Planned/proactive (proactive adaptation)                            | X            | X | X | X |
| <b>Who participated in the decision to modify?</b>                  |              |   |   |   |
| Lead researcher                                                     | X            | X | X | X |
| Research supervisors                                                | X            |   |   | X |
| Parent stakeholders                                                 | X            | X |   |   |
| Clinical Psychologists working within children's autism services    |              |   | X | X |
| <b>What is modified?</b>                                            |              |   |   |   |
| Content                                                             | X            | X | X | X |
| Contextual                                                          | X            |   |   |   |
| <b>At what level of delivery for whom the modification is made?</b> |              |   |   |   |
| Target intervention group                                           | X            | X | X | X |
| Cohort/Individuals that share a particular characteristic           | X            | X | X | X |
| Practitioners                                                       |              |   |   | X |
| <b>Contextual modifications are made to which of the following?</b> |              |   |   |   |
| Format                                                              | X            |   |   |   |
| Personnel                                                           | X            |   |   |   |
| Population                                                          | X            |   |   |   |
| <b>What is the nature of the content modification?</b>              |              |   |   |   |
| Adding elements                                                     | X            | X | X | X |
| Lengthening/extending (pacing/timing)                               |              |   | X |   |
| Loosening structure                                                 |              | X |   | X |
| Removing/skipping elements                                          | X            |   |   |   |
| Reordering of intervention modules or segments                      | X            |   |   | X |
| Repeating elements                                                  | X            |   |   |   |
| Shortening/condensing (pacing/timing)                               | X            | X |   |   |
| Substituting                                                        | X            |   |   |   |
| Breaking up session content over multiple sessions                  | X            |   |   | X |
| Tailoring/tweaking/refining                                         | X            | X | X | X |

<sup>39</sup> See section 3.5 and 3.6 in extended for examples of how the CMT workbook was adapted following relevant guidance.

| <b>Process</b>                                           | <b>Phase</b> |   |   |   |
|----------------------------------------------------------|--------------|---|---|---|
|                                                          | 1            | 2 | 3 | 4 |
| <b>What was the goal?</b>                                |              |   |   |   |
| Increase reach or engagement                             | X            | X | X | X |
| Increase retention                                       | X            |   |   |   |
| Improve feasibility                                      | X            | X | X | X |
| Improve fit with recipients                              | X            | X | X | X |
| To address cultural factors                              | X            |   | X | X |
| Improve effectiveness/outcomes                           | X            | X | X |   |
| Increase satisfaction                                    |              | X | X |   |
| Reduce cost                                              | X            |   |   |   |
| <b>Relationship fidelity/core elements?</b>              |              |   |   |   |
| Fidelity consistent/core elements or functions preserved | X            | X | X | X |
| <b>Reasons</b>                                           |              |   |   |   |
| Access to resource                                       | X            |   |   |   |
| Available resources                                      | X            |   |   |   |
| Cognitive capacity                                       | X            | X | X |   |
| Comorbidity/Multimorbidity                               | X            | X | X |   |
| Crisis or emergent circumstances                         | X            | X |   | X |
| Cultural norms                                           | X            |   | X |   |
| Literacy and education level                             | X            | X | X | X |
| Motivation and readiness                                 | X            | X | X | X |
| Perception of intervention                               | X            |   |   |   |
| Service structure                                        | X            |   |   |   |

Following de-duplication of adaptation suggestions extracted during the DCA, a total 107 of 164 suggestions were implemented. Twenty-seven suggestions were not implemented due to being already present or deemed inappropriate as these contradicted core components of CMT. Thirty suggested adaptations were not implemented yet due to restrictions on available resources but were noted for future consideration.

PAC feedback in FG1 regarding the original resource was largely negative. Criticisms related to perceived high intervention burden due to large amounts of text and complex language to read, lack of clarity around purpose and coherence of the intervention, and lack of specificity to parenting an autistic child. Consequently, the research team chose to re-write the workbook material, as this was more time efficient than adapting the resource so significantly. *Compassionate Mind Training for Parents of*

*Autistic Children* (CMT-PAC) was created as a six-week intervention with accompanying audio tracks for daily practice. It incorporated more diagrams, text boxes, colour-coding and autism-specific examples recommended during FG1. PAC feedback within FG2 was subsequently largely positive, and further amendments involved use of more examples to increase clarity of psychoeducation components, and minor alterations to colours and formatting.

CP adaptation suggestions in phase three largely involved making language informal and breaking some psychoeducation elements into smaller sections. Character stories and reflective spaces were also added to strengthen future recipients' understanding and practice. Following CP feedback in FG3, final adaptations included minor format changes; re-ordering chapters one and two to introduce challenges in parenting prior to the theoretical background of CMT; addition of a compassionate object exercise in chapter six; and splitting of a compassionate imagery exercise into shortened and extended versions to enhance accessibility.

The taxonomic analysis provided further context regarding reasons why adaptations were made per feedback phase, as shown in Table 3. This revealed that only 30 of 91 possible combinations for adaptation types were undertaken, where most were categorised as tailoring, tweaking, or refining the intervention ( $n=86$ ). Reasons for adaptation were most commonly to increase reach and engagement ( $n=25$ ), to increase fit with recipients ( $n=37$ ), and to improve feasibility ( $n=15$ ).

**Table 3**

*Why did Adaptations Occur During Each Phase?*

| <b>What was adapted?</b>                  | Reach / Engagement | Increase retention | Improve feasibility | Fit with recipients | Cultural factors | Effectiveness / Outcomes | Reduce cost | Increase satisfaction |
|-------------------------------------------|--------------------|--------------------|---------------------|---------------------|------------------|--------------------------|-------------|-----------------------|
| Adding Elements <sup>a</sup> (n=13)       | 0:0:0:0            | 1:0:0:0            | 0:0:1:0             | 0:0:1:1             | 0:0:1:0          | 5:1:2:0                  | 0:0:0:0     | 0:0:0:0               |
| Lengthening/ Extending <sup>a</sup> (n=1) | 0:0:0:0            | 0:0:0:0            | 0:0:0:0             | 0:0:1:0             | 0:0:0:0          | 0:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Loosening Structure <sup>a</sup> (n=2)    | 0:0:0:0            | 0:0:0:0            | 0:1:0:1             | 0:0:0:0             | 0:0:0:0          | 0:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Removing Elements <sup>a</sup> (n=2)      | 0:0:0:0            | 0:0:0:0            | 0:0:0:0             | 1:0:0:0             | 0:0:0:0          | 0:0:0:0                  | 1:0:0:0     | 0:0:0:0               |
| Re-ordering Modules <sup>a</sup> (n=3)    | 0:0:0:0            | 0:0:0:0            | 0:0:0:0             | 1:0:0:0             | 0:0:0:1          | 1:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Repeating Elements <sup>a</sup> (n=1)     | 0:0:0:0            | 0:0:0:0            | 0:0:0:0             | 0:0:0:0             | 0:0:0:0          | 1:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Shortening/ Condensing <sup>a</sup> (n=4) | 0:0:0:0            | 0:0:0:0            | 3:1:0:0             | 0:0:0:0             | 0:0:0:0          | 0:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Spreading Content <sup>a</sup> (n=2)      | 0:0:0:0            | 0:0:0:0            | 0:0:0:1             | 0:0:0:0             | 0:0:0:0          | 1:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Substituting Content <sup>a</sup> (n=1)   | 0:0:0:0            | 0:0:0:0            | 0:0:0:0             | 0:0:0:0             | 1:0:0:0          | 0:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Tailoring Content <sup>a</sup> (n=86)     | 5:4:12:1           | 4:0:0:0            | 3:1:1:0             | 4:6:18:3            | 5:0:1:0          | 0:0:3:0                  | 0:0:0:0     | 0:9:6:0               |
| Intervention Format <sup>b</sup> (n=3)    | 1:0:0:0            | 0:0:0:0            | 1:0:0:0             | 1:0:0:0             | 0:0:0:0          | 0:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Intervention Personnel <sup>b</sup> (n=1) | 1:0:0:0            | 0:0:0:0            | 0:0:0:0             | 0:0:0:0             | 0:0:0:0          | 0:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| Target Population <sup>b</sup> (n=2)      | 1:0:0:0            | 0:0:0:0            | 1:0:0:0             | 0:0:0:0             | 0:0:0:0          | 0:0:0:0                  | 0:0:0:0     | 0:0:0:0               |
| <i>Total adaptations by phase:</i>        | 8:4:12:1           | 5:0:0:0            | 8:3:2:2             | 7:6:20:4            | 6:0:2:1          | 8:1:5:0                  | 1:0:0:0     | 0:9:6:0               |

*Note.* n:n:n:n refers to phases of adaptation (i.e., phase 1 : phase 2 : phase 3 : phase 4); <sup>a</sup> Content Modification; <sup>b</sup> Contextual Modification

**Anticipated factors influencing successful implementation of CMT-PAC during future testing**

The conducted FA involved all focus group data. Table 4 shows the development of two key concepts as a result.

**Table 4**

*Key Concepts Developed from Initial Categories and Themes*

| <b>Initial Categories</b>                                                                                                                                                                                                                                                                                                                                                                               | <b>Final Themes</b>              | <b>Key Concepts</b>                           |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------|-----------------------------------------------|
| <ul style="list-style-type: none"> <li>• <i>Challenges in parenting</i></li> <li>• <i>Parental constraints</i></li> <li>• <i>Parents' concerns and priorities</i></li> </ul>                                                                                                                                                                                                                            | Role as a parent                 | <b>Personal and Social Context of Parents</b> |
| <ul style="list-style-type: none"> <li>• <i>Parental mental health</i></li> <li>• <i>Negative self-evaluation</i></li> <li>• <i>Prevalence of trauma histories in parents</i></li> </ul>                                                                                                                                                                                                                | Parental mental health           |                                               |
| <ul style="list-style-type: none"> <li>• <i>Bureaucracy in services</i></li> <li>• <i>Gaps in services</i></li> <li>• <i>Potential value of CMT in services</i></li> <li>• <i>Diagnosis as the gateway to support</i></li> </ul>                                                                                                                                                                        | Services around the parent       | <b>Facilitators and Barriers</b>              |
| <ul style="list-style-type: none"> <li>• <i>General accessibility considerations</i></li> <li>• <i>Applicability constraints</i></li> <li>• <i>Fluctuating engagement dynamics</i></li> <li>• <i>Perceived feasibility of intervention</i></li> <li>• <i>Importance of accessibility options</i></li> <li>• <i>Value of guided support</i></li> <li>• <i>Parents' learning support needs</i></li> </ul> | Accessibility and learning needs |                                               |
| <ul style="list-style-type: none"> <li>• <i>Influence of prior knowledge</i></li> <li>• <i>Understanding of the CMT process</i></li> <li>• <i>Preference for autism specific</i></li> <li>• <i>Perceived target audience</i></li> </ul>                                                                                                                                                                 | Knowledge and understanding      |                                               |
| <ul style="list-style-type: none"> <li>• <i>Perceptions around compassion</i></li> <li>• <i>Needing to feel understood</i></li> <li>• <i>Activating the soothing system</i></li> <li>• <i>Attitude towards intervention tone</i></li> </ul>                                                                                                                                                             | Psychological needs              |                                               |

Note. CMT = Compassionate Mind Training.



## Personal and Social Context of Parents

This concept focused on PAC's experiences of navigating parenthood and services, to share insight into how future recipients' contexts may influence their motivation and ability to engage with CMT-PAC. It also provided participant's views around the potential value of CMT-PAC. It comprised of three themes, described below with accompanying quotes.<sup>40</sup>

**Role as a parent.** Groups highlighted various parenting demands that could impact on PAC engagement with a psychological intervention, including childcare commitments, difficulties maintaining a usual routine, and likelihood of unexpected interruptions. Parents within FG1 shared having limited time and energy and considered strategies to use CMT-PAC alongside fulfilling their parenting duties, such as through listening to an audiobook version or trying CMT exercises with their child, if appropriate. CPs recognised the likelihood that parents' engagement will fluctuate due to pressures associated with parenting.

*you've got children with autism, it is difficult. –Mo (parent, FG1)*

*there will be other times when life gets in the way and you bench it [...] it will become something that sits on the kitchen table that you might dip in and out of, and forget about, then come back to –Shona (CP, FG3)*

Furthermore, parents in FG1 recognised their reasons to seek CMT-PAC would be likely related to wanting answers or a 'fix' to manage their stressful situational context, which is not necessarily provided by CMT-PAC. One parent shared their prioritisation to help their children over themselves. Therefore, it was felt that the potential mismatch between PAC motivators versus aims of CMT-PAC could lead to

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<sup>40</sup> See section 3.7 in extended for further participant quotes for all Framework Analysis themes.

disengagement by some. However, CPs reflected that it is often parents that would likely benefit from intervention, rather than their children.

*it's not telling me what I need to do in a certain situation, or how I'm gonna [...] combat this –Jane (parent, FG1)*

*how many times [...] that the reason that a referral is coming in isn't because we can suddenly wave a magic wand and make a child less autistic, it's because parents are just overwhelmed –Shona, (CP, FG3)*

**Parental mental health.** All groups highlighted poorer mental health outcomes in PAC, acknowledging a need for intervention whilst also recognising that some PAC may lack headspace to engage when reactively help-seeking under significant stress. Additionally, CPs considered possibilities of PAC experiencing trauma, and how self-compassion could subsequently be experienced as uncomfortable or 'triggering' by some in this context. CPs highlighted that CMT-PAC remained appropriate in these circumstances but advised that facilitators consider possibility of unexpected distress by PAC during CMT practices and advocated for guided support to manage this. Finally, negative self-evaluation was evident in both PAC groups, where they described shame and self-criticism in relation to their parenting approaches, including their beliefs around being able to complete aspects of CMT-PAC as prescribed. This evidences potential need for CMT-PAC but indicates a possible factor influencing future recipient dropout.

*that's quite common I think that the parents we see, they've often experienced some really tricky stuff –Jan (CP, FG3)*

*there's a sentence that says, 'this is not your fault, this is not your fault' and I found that, you know, no one ever really says that to you, so, and you do blame yourself for everything! –Josie (parent, FG2)*

**Services around the parent.** PAC shared their negative experiences with mental health services, including difficulties obtaining a referral for their child's autism assessments and long waiting times to be seen. They highlighted their belief that accessing service support was contingent on their child receiving an autism diagnosis. Similarly, CPs acknowledged that CMT-PAC could be a valuable waitlist intervention, as absence of a child's diagnosis should not prevent access to preventative care.

*that seems to be the experience of many parents that I've spoken to [...] years battling and fighting –Jane (parent, FG1)*

*I thought the same about the [...] waiting list stuff and maybe pre-diagnosis, that it could be useful –Tara (CP, FG3)*

Furthermore, parents shared their experiences around a perceived lack of post-diagnostic support, which was felt to have been warranted. Similarly, CPs recognised structural gaps in services due to clinical thresholds between primary and secondary mental health services, a lack of variety in therapeutic modalities offered by services, and a lack of commissioning for parent focussed work, which they felt required addressing. These factors evidence potential value of preventative interventions for this population, such as CMT-PAC, as they could be increasingly sought and accessed by PAC as an alternative to seeking service involvement, particularly by parents with negative service experiences. However, one parent shared concerns that CMT-PAC may become offered by services as a box-ticking exercise before direct work is considered and advised that developers consider how the CMT-PAC is sold to future recipients.

*I think it's a really important bit of work that's often missing from services because we're not really commissioned to do parent work, but actually, that's the work that often needs to be done –Jan (CP, FG3)*

*I was just trying to rack my brains [...] about whether I've seen anything else, but I haven't. –Polly (CP, FG3)*

*I'd be interested in using it, if it wasn't sold as a replacement to something else or would push you down the waiting list. -Rachel (parent, FG2)*

## **Facilitators and Barriers**

This concept captured anticipated factors underpinning stakeholders' adaptation requests, to make CMT-PAC more successfully implementable during future studies. It comprised of three themes, described below with accompanying quotes.

**Accessibility and learning needs.** Both PAC and CP groups shared that guided support would increase intervention uptake by PAC compared to self-help, as this would provide an accountability check-in space and troubleshooting if needed. All groups considered ways to generally support recipients' learning needs through use of colour, visuals, and reducing amount of text. All groups highlighted the likelihood that some PAC will be neurodivergent themselves, so further considerations were made around making instructions more explicit, providing choice in communication preferences for guided support elements, and providing troubleshooting information for those with interoception differences, or when imagery or body-based exercises may be harder to access. It was recognised that no intervention can be made truly universally accessible, but that it was important to make the original CMT resource accessible to more.

*parents of autistic children don't need self-help, they need help –Rachel (parent, FG1)*

*sometimes you have to be careful with abstract stuff or too much imagery, [...] especially if we're wondering if some of the parents might also be neurodivergent –Tara*  
(CP, FG3)

*when you're looking for an intervention that will go to the masses, there's always going to be some groups of people that don't have that sort of way of thinking, or different hurdles for different people –Shona (CP, FG3)*

Furthermore, all groups highlighted that parents' engagement with CMT-PAC would likely fluctuate, so recommendations included validation of PAC's efforts and advocacy for flexible use of the tool to increase PAC's confidence to return to the intervention. Groups emphasised the importance of providing options and choice to flexibly engage with CMT-PAC through different intervention and guided support formats, and type and length of exercises to meet a broader range of recipients' preferences and learning needs. During FG2, all PAC anticipated that CMT-PAC could be feasible for future study participants to complete.

*it's got to be really flexible, I would say. -Rachel (parent, FG1)*

*it's a bit like when you do a yoga class and there's different options depending on where your body's at. It's your compassion muscle I guess that you're testing. –Jan*  
(CP, FG3)

*I think it is definitely do-able, to do it week-by-week –Josie (parent, FG2)*

**Knowledge and understanding.** PAC in FG1 requested increased clarity around purpose and rationale for intervention components, to support recipients' informed decision-making to engage with CMT-PAC. For example, one parent highlighted that psychoeducation elements in the original resource, such as the 'tricky brain', appeared irrelevant as they viewed only experiential elements as being "*the therapy*" rather than the whole intervention.

*you're not learning about what compassionate theory is for your research project, you're doing the therapy, so I think that's what it needs to focus on, doing the therapy with the option of learning more about it alongside. Um, at the moment it's focused on the theoretical aspect of it, with the actual therapy on the side. –Rachel (parent, FG1)*

All groups emphasised value and need for autism-specific interventions that would likely match PAC's experiential knowledge. PAC in FG1 shared negative emotional responses towards general content in the original resource that was perceived to not apply to their own children, such as developmental milestones of typically-developing children. CPs later commended the autism-specific nature of the updated CMT-PAC and highlighted its potentially protective nature for parental mental health, arising from PAC becoming connected with the 'autism identity'.

*I want this to be talking to me as a parent, and me [...] as a parent of an autistic child, and there was nothing really in there that was talking to me in that sense, it was very, very general –Jane (parent, FG1)*

*having ASD in the intro, or you know the title, I think that might be quite important in some ways because there's a lot of that, sort of, autism identity, and that in itself has, um, a massive protective factor for mental health –Shona (CP, FG3)*

Both stakeholder groups felt that potential recipients would require a level of education to access the resource, although guided support elements were anticipated to increase engagement with a more diverse range of PAC with varied educational backgrounds. One PAC shared their prior interest around mindfulness approaches and felt that the original resource may not be helpful for those with a good understanding of these approaches already, or where PAC may exhibit learning needs around their child's autism-related support needs.

*when you've got a child that's got sensory issues, if you're maybe at a point where you don't understand those sensory issues, trying to apply the principles of compassion still doesn't cut it, because you're not knowing why they're still having a meltdown, so you, for all the compassion in the world, if you don't understand that side, this still probably wouldn't be very helpful. -Jane (parent, FG1)*

*I think yeah for people that are educated [...] say people who are like reading a lot, they would like it –Mo (parent, FG1)*

**Psychological needs.** Parents shared varying prior knowledge about the concept of compassion, including being unaware or less experienced with self-compassion, and held varying beliefs around value of a compassionate mindset. Similarly, CPs shared clinical experiences where PAC's self-compassion appeared blocked or harder to tolerate but described optimism about using CMT with this population and highlighted potential well-being benefits for PAC and their children. Furthermore, all groups highlighted the importance of modelling compassion to PAC to increase retention during future studies. Participants shared strategies to model compassion through upholding a compassionate tone within written and guided components, and normalisation of stumbling blocks to de-shame PAC's experiences, should aspects of CMT-PAC seem difficult to complete.

*we often focus on being compassionate towards other people but in all honesty, before I started reading this, it wasn't something that I'd thought about being a self thing –*  
Josie (parent, FG2)

*it isn't something that you're just going to get straight away, and [...] things aren't going to be perfect; it's going to take time and there will be stumbling points and [...] part of that is about saying to people 'that's okay' and [...] it's a learning curve –Tara (CP, FG3)*

Finally, all groups discussed value attached to PAC perceiving that they are truly understood by the intervention developers, basing this on tone and content of intervention materials. PAC felt this would increase potential acceptability for future study participants. CPs shared recommendations around further use of common themes experienced by PAC from the beginning of the workbook, to enable parents to feel understood from the outset.

*it sounded like you were like, putting yourself in a parent's shoes and you have that understanding, and I thought it was really, really well written, yeah, and I enjoyed it –*

Olivia (parent, FG2)

### ***Theoretical Consistency and Final Comments***

All CPs during phase four shared that CMT-PAC remained theoretically consistent post-adaptation. During phase five, written commentaries were requested from two CFT experts regarding whether theoretical coherence was maintained. Copies were re-distributed to four PAC participants with an optional invitation to provide further feedback, but none was received. Feedback was received from one CFT clinician<sup>41</sup>, who held clinical and research expertise regarding use of CFT with parents:

*This workbook is a wonderful resource for parents of autistic children. All the material and exercises are consistent with the theory and models that underpin Compassion Focused Therapy. [...] This CMT workbook is highly applicable and likely to be very helpful for parents of autistic children. –CFT expert*

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<sup>41</sup> See section 3.8 in extended for full feedback received from the CFT expert.



## Discussion

This study aimed to explore adaptations needed to use a CFT resource as a guided self-help intervention with PAC and define anticipated factors influencing successful implementation during future feasibility testing. The original resource was deemed inappropriate for PAC by key stakeholders and required significant adaptation, largely aiming to increase feasibility, fit, and engagement. Stakeholders described optimism about the final CMT-PAC, and CFT clinicians deemed theoretical coherence was maintained post-adaptation. Several facilitators, barriers, and contextual factors are anticipated to influence implementation of CMT-PAC. Major findings recognised broadly across analyses are discussed further, and several clinical and research implications are provided.

### ***Compassion and the Therapeutic Relationship***

PAC highlighted several key facilitators for engagement, including the wish to feel understood by intervention developers, perceived through validation and an 'affirming' rather than 'instructional' tone. These preferences may relate to key attributes of compassion, such as non-judgement and empathy (Gilbert, 2009), highlighting potential value from modelling a compassionate stance on intervention outcomes. Self-Determination Theory<sup>42,43</sup> (Deci & Ryan, 1980, 1985, 2012) might further explain motivational processes from using a compassionate tone, where an autonomy-supportive approach could be anticipated to increase recipients' motivation and perceived competence to use the resource effectively within their context. Furthermore, the shared preference for guided support may be an integral method to

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<sup>42</sup> See section 4.1 in extended for definition of Self-Determination Theory.

<sup>43</sup> See section 4.2 in extended for detailed application of Self-Determination Theory to research findings.

promote recipients' autonomy and competence to foster ongoing engagement, motivation and value of compassion cultivation (Ryan & Deci, 2022).

Importantly, this finding reveals the anticipated role of the therapeutic relationship between PAC and the CMT-PAC workbook as a key facilitator for engagement, which has important clinical implications related to how CFT interventions are adapted and delivered with this population. Common factors in psychotherapy (Rosenzweig, 1936) such as flexibility, responsiveness, and therapeutic alliance were recognised by stakeholders as crucial aspects anticipated to increase effectiveness of CMT (Petrocchi et al., 2024) and should be interwoven into CFT self-help materials. Richardson et al. (2010)<sup>44</sup> previously hypothesised that a lack of common factors within non-guided self-help would impair intervention performance, and the present findings build on this through evidencing this need expressed by target intervention recipients.

### ***Fear of Compassion***<sup>45</sup>

Stakeholders described potential adverse effects from CMT exercises, including fears of failure, or future recipients experiencing compassion as threatening or aversive. Fears of compassion (Gilbert et al., 2011) can be marked within highly self-critical groups (Kirby, Day, et al., 2019; Merritt & Purdon, 2020), particularly if people have experienced traumatic, abusive or neglectful backgrounds (Gilbert & Procter, 2006; Matos et al., 2017; Winders et al., 2020). Although high levels of self-criticism are well-evidenced within PAC populations (Bohadana et al., 2019; Sirois et al., 2019), no research publications have yet identified fears of compassion within PAC. Bohadana et al. (2019) also identified barriers to self-compassion amongst PAC, although

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<sup>44</sup> See section 4.3 in extended for further discussion regarding common factors applied in self-help.

<sup>45</sup> See section 4.4 in extended for further discussion regarding fears of compassion.

interpreted these as mindfulness difficulties and competing priorities, which may also be attributed to PAC fears of failure around completing CMT-PAC as directed.

Fear of compassion could decrease CMT-PAC engagement and retention if not primarily addressed. Techniques to approach and work through an individual's fears and resistance towards compassion can provide an important therapeutic effect (Gilbert, 2010). Therefore, a clinical implication concerns incorporating fears of compassion into screening procedures for PAC accessing CFT interventions, to inform whether further intervention is required, echoing Merritt and Purdon (2020). This is particularly relevant for interventions that are largely self-directed and could be a focus within guided support opportunities.

### ***Intervention-Context Fit***

In accordance with previous research, stakeholders emphasised poor PAC mental health outcomes, high competing parenting demands, gaps in service delivery, and barriers to accessing psychological support (Bohadana et al., 2019; Osborn et al., 2020; Schnabel et al., 2020; Wallace-Watkin et al., 2023). All PAC attending FG2 shared that CMT-PAC appeared feasible and described interest to use the materials, highlighting the potential value of guided self-help resources to increase PAC access to preventative psychological interventions, in line with broader initiatives recognised in the NHS (2019) Long Term Plan.

Flexible engagement options could be viewed as another autonomy-supportive approach, to enhance PAC alliance with the intervention and its fit alongside contextual factors. In contrast, close attention to implementation fidelity is often seen as a requirement when conducting behavioural-intervention efficacy research, to decrease

presence of confounding variables that may influence evaluation of treatment integrity<sup>46</sup> (Johnson & Remien, 2003; Persch & Page, 2013). However, concerns identified by stakeholders in the present study are reflected elsewhere, with arguments that rigid psychological therapy protocols may not be suitable for complex client presentations in community settings (Addis et al., 1999; Mazzucchelli & Sanders, 2010). Furthermore, systematic reviews have recognised that therapist adherence and manualised treatment are not empirically supported as more effective than variable adherence or non-manualised treatment, across a range of presentations including anxiety, depression, and trauma-related, and use of interventions including CBT, family therapy and attachment-based therapy (Truijens et al., 2019; Webb et al., 2010). There is currently no empirical evidence regarding the relationship between adherence to CFT protocol and treatment outcomes, likely as the first practice manual is due for publication later this year (Petrocchi et al., 2024).

### ***Diverse Learning Needs***

Increased prevalence of parental neurodivergence was identified by all stakeholder groups. Despite increasing evidence that PAC often exhibit sub-diagnostic threshold autistic traits, defined as the 'broader autism phenotype' (Pruitt et al., 2018; Rubenstein & Chawla, 2018; Wheelwright et al., 2010), and evidence suggesting autism aetiology is partly genetic (Warrier & Baron-Cohen, 2017), there is a lack of research regarding autistic parents (Fletcher-Randle, 2022; Pohl et al., 2020), and no prevalence estimates for autistic PAC. Regardless, the recognised prevalence of autistic traits within PAC held important clinical implications regarding increasing the accessibility of CFT interventions for PAC, and subsequently influenced the nature of

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<sup>46</sup> See section 4.5 in extended for details around the debate between implementation protocol versus clinical flexibility.

many adaptation suggestions related to broader 'autism-friendly' principles<sup>47</sup> (NICE, 2021a).

Potential autism-related contraindications were highlighted which require further consideration and could result in changes to the delivery of usual CMT exercises, relating to differences in interoception and imagery abilities. However, during the present research, two small-scale feasibility studies of compassion-based interventions with autistic adults were published, which included imagery tasks (Edwards et al., 2024; Riebel et al., 2024)<sup>48</sup>. These provide tentative evidence that such approaches appeared feasible for participants, although conclusions cannot be generalised as autism-related learning differences are known to be varied and individualised (Nader et al., 2022). Practical implications<sup>49</sup> include consideration of PAC learning needs during CFT screening processes. Alternative tangible CMT exercises are emerging, such as the Compassionate Kitbag (Lucre & Clapton, 2021) which promote inclusion from recipients with a broader range of accessibility and learning needs and could be used when imagery tasks appear inaccessible.

### ***Strengths and Limitations***

This study provides a novel contribution to clinical psychology literature, through the creation of a culturally-adapted CMT intervention, and by documenting key stakeholder insights around the appropriateness of its delivery through guided self-help. Furthermore, this study adds to a growing body of literature to detail stakeholder-informed adaptation processes using qualitative methods. The study adhered to

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<sup>47</sup> See section 4.6 in extended for details around 'autism-friendly' adaptation principles.

<sup>48</sup> See section 4.7 in extended for details around small-scale compassion-based intervention studies with autistic adults.

<sup>49</sup> See section 4.8 in extended for further implications not yet discussed in the journal or extended papers.

recommendations for adaptation of complex health interventions (Kirk et al., 2020; Moore et al., 2021; Skivington et al., 2021a), reporting guidelines (Stirman et al., 2019), and involvement of people with lived experience to adapt mental health interventions, which may support acceptability, feasibility, and intervention appeal for this target population group (Bell et al., 2023).

However, the study was limited<sup>50</sup> by the failure to recruit the anticipated number of parents to attend both focus groups, and only a small number of CPs. Participants shared homogenous demographics, meaning that adaptation suggestions from those from other backgrounds may have been missed. Additionally, dominant voices were prevalent in all focus groups, despite attempts to moderate discussion to re-balance contributions from all participants, which may mean that inevitably some participant views remained unspoken or silenced (Kitzinger, 1995). There was risk that adaptations completed from later rounds of feedback unintentionally contradicted recommendations from earlier rounds. Attempts to prevent this included thorough documentation of adaptation processes and the final resource being disseminated to all participants who had opted to receive a copy, but no further feedback was received.

### ***Future Research Directions***<sup>51</sup>

The current research indicates several implications for research and justifies a pilot study to assess the feasibility and utility of CMT-PAC, following complex intervention development guidelines (Skivington et al., 2021a). Findings from a pilot testing phase can inform the appropriateness of progression to a randomised controlled trial, to further the evidence base regarding utility of CFT guided self-help

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<sup>50</sup> See section 4.9 in extended for detailed study limitations.

<sup>51</sup> See section 4.10 in extended for further future research directions.

interventions for PAC. Future research should investigate how fear of compassion is experienced by PAC, to inform how this is assessed and managed when CMT-PAC is studied. The request for promotion of flexible engagement options raises considerations regarding how adherence to protocol is appropriately measured during feasibility testing. Finally, the likelihood of neurodivergent adults accessing CMT-PAC in practice is recognised, so further studies investigating the effectiveness of compassion-based interventions with autistic adults are warranted, echoing Mason et al. (2023).

### ***Conclusion***

This study adds to growing literature relating to the applicability of compassion-based interventions for PAC and extends it by creating a stakeholder-informed CMT intervention for this population. Studies such as this create a promising foundation for further testing of compassion-based interventions with PAC and highlights the value of stakeholder engagement during adaptation processes, as is recommended within various intervention development frameworks (Moore et al., 2021; Skivington et al., 2021a) yet is still often missed (O’Cathain et al., 2019). Future research should assess CMT-PAC to ascertain feasibility in practice, and to answer queries raised about how it is experienced and utilised by PAC.

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### **Statement of Contribution**

The first author led project design, ethical application, participant recruitment, data collection, data analysis, intervention adaptation, and writing the report. The second and third authors supervised the study design, ethical approval process, data analysis and write up. The fourth author assisted data collection and intervention adaptation.

## Extended Paper

## 1.0 Extended Background

### 1.1 Definition of Autism

Autism Spectrum Disorder is a lifelong neurodevelopmental condition that is defined in the latest version of the Diagnostic and Statistical Manual (DSM-5; American Psychiatric Association [APA], 2013) as having persistent differences in social communication and social interaction, and restricted, repetitive patterns of behaviour, interests, or activities which contribute to clinically significant impairment in a person's social, occupational, or other areas of current functioning. Such differences are often recognised during the early developmental period, although may not be identified until later in life, where social demands may exceed a person's capacity (Daniels & Mandell, 2014; Huang et al., 2020; Shaw et al., 2022; Van 'T Hof et al., 2021). Differences are not better explained by the presence of an intellectual disability or global developmental delay (APA, 2013; British Psychological Society [BPS], 2022; World Health Organization, 2019). The condition is highly complex, with the above diagnostic criteria recognising significant diversity within the autistic population including heterogeneity across IQ, language abilities, social, and behavioural functions (Unwin et al., 2013). Therefore, an autistic person's relative strengths and support needs associated with the condition are understood as highly individualistic (Ure et al., 2018).

Understandings around autism have evolved over time, with the DSM-5 unifying three previously separate diagnoses of autistic disorder, Asperger's disorder and pervasive developmental disorder – not otherwise specified (APA, 2013). The aetiology of autism is not yet well understood, although current evidence suggests this is multifactorial and may comprise of genetic, environmental, and pre- and post-natal influences (Sauer et al., 2021). Given the significant heterogeneity of the condition and lack of validated clinical biomarkers to support diagnostic assessment, the use of clinical practice guidelines for assessment is imperative to support evidence-based, good quality behavioural assessment methods whilst reducing risk of potential under-identification of people with autism in the United Kingdom (Huerta & Lord, 2012; Jensen et al., 2022). Systematic reviews of practice guidance in the United Kingdom (Hayes et al., 2018) alongside those published in Canada and America (Penner et al., 2018) reveal variability in recommendations for use of diagnostic tools, which types of professionals should be involved in an assessment, and which data sources should be considered (i.e., behavioural observations, self-report, and informant-report from

caregivers and education provider where appropriate). Both reviews indicated that guidelines often recommend a multidisciplinary approach, although specifications around how this approach is utilised is less clear. Widely used psychometric instruments for autism assessments within the United Kingdom currently include the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord, Luyster, et al., 2012; Lord, Rutter, et al., 2012), the Autism Diagnostic Interview, Revised (ADI-R; Rutter et al., 2003), the Diagnostic Interview for Social and Communication Disorders (DISCO; Leekam et al., 2002) and the Developmental, Dimensional and Diagnostic Interview (3di; Skuse et al., 2004).

There is no single preferred term to describe autism, with examples including 'having autism', 'on the autism spectrum' and 'autistic'. The use of 'person-first' language (i.e., 'an autistic person', rather than 'a person with autism') is consistently highly endorsed as a preferred terminology by autistic adults and their families within the United Kingdom, but terminology used by professionals is more variable (Botha et al., 2023; Kenny et al., 2016). To honour the diverse preferences of the United Kingdom population, person-first and identity-first terms are used interchangeably both throughout the present research and within the adapted intervention.

## **1.2 Mental Health Outcomes for Parents of Autistic Children**

There is a wealth of evidence surrounding the poorer mental health outcomes identified within parents of autistic children (PAC). The most prominent outcomes explored within this population are broadly defined below.

**Parenting stress.** This outcome is the most frequently researched relating to the parental mental health of PAC and has been largely attributed to result from the experience and management of their children's behaviour that may challenge (Bonis, 2016). There is ample evidence recognising higher rates of parenting stress amongst PAC, in comparison to parents of typically-developing children (Barroso et al., 2018; DesChamps et al., 2020; Hayes & Watson, 2013) and parents of children with other disabilities, including Downs Syndrome (Dabrowska & Pisula, 2010) and intellectual disability (Totsika et al., 2011).

**Life satisfaction.** The population of PAC are evidenced to experience lower life satisfaction than parents of typically-developing children (Lu et al., 2015) and may experience lower relationship satisfaction than couples raising a child without disability

(Sim et al., 2016). A study investigating health-related quality of life reported reduced levels amongst a sample of PAC in comparison to normative populations (Kuhlthau et al., 2014).

**Psychopathology.** Estimated prevalence rates for parental anxiety have indicated high levels within this parenting population (Hayes & Watson, 2013; Machado Junior et al., 2014). Similar findings are recognised during screening for depressive symptoms (Hayes & Watson, 2013; Machado Junior et al., 2014; Piro-Gambetti et al., 2023). A recent systematic review and meta-analysis by Schnabel et al. (2020) reported median meta-analytic proportions for psychological disorders in a total sample of 9208 PAC across 31 articles. The review findings are a cause of concern; depressive disorders and anxiety disorders were seen to have prevalence rates of 31% in 4415 parents, and 33% in 2442 parents, respectively. These results are significantly higher than the estimated 5% and 4% global prevalence rates in the adult general population (World Health Organization, 2023a, 2023b). However, this finding also suggests that approximately two-thirds of PAC may not experience clinical levels of depression or anxiety, which may indicate that many PAC develop positive coping strategies in the face of challenging parenting events. Obsessive compulsive disorder in parents was seen to have a combined prevalence of 10%, although this disorder was only evaluated in three studies (total  $n=145$ ). Total prevalence for personality disorders, alcohol and substance use disorders, and schizophrenia spectrum disorders, indicated prevalence rates that appeared in line with the global population.

### **1.3 Factors Influencing the Mental Health of Parents of Autistic Children**

Several specific factors relating to the experience of parenting an autistic child/ren are increasingly recognised as influencing parental mental health within this population. PAC are likely to experience unique differences within their caregiving role towards their child, which may affect parental mental health and wellbeing (Khan et al., 2016). Receiving the autism diagnosis itself can significantly influence family dynamics, where many parents are reported to undergo a grief-like experience with uncertainties about their family's future following a perceived loss of usual expectations associated with a 'typically-developing' child (Legg & Tickle, 2019; Rabba et al., 2019). A recent systematic review evidenced that many parents experienced the dismissal of their concerns from others whilst advocating for their child's autism assessment and disclosed moral dilemmas around seeking a diagnosis for their child, contributing to a

variety of distressing experiences including confusion, guilt, self-blame, shock, and anger (Legg & Tickle, 2019).

Such challenges are likely exacerbated by the current significant delays for autism assessments throughout the NHS. Available statistics have shown that in March 2023, 84% of those awaiting an autism assessment in England have waited longer than the recommended 12-weeks between referral and first contact, as specified within guidelines by the National Institute for Health and Care Excellence (National Autistic Society, 2023; National Institute for Health and Care Excellence [NICE], 2017; NHS Digital, 2023). Delays or unequal access to autism assessment may prevent access to evidence-based autism-specific interventions for autistic children and can result in missed opportunities for reasonable adjustments in health, care and educational settings (NHS England, 2023). Consequently, access to specific PAC mental health support may be also further limited for those awaiting their child's acquisition of an autism diagnosis (Crane et al., 2016).

Furthermore, the vast range of differences in autistic children's social interaction skills and behaviours will likely require adaptations to parents' caregiving approaches and understanding of their child (McStay et al., 2015). Parents who are perhaps inexperienced due to having limited understanding around the diagnosis, or who are a first-time parent, may face detrimental emotional consequences (Khan et al., 2016; Roquette Viana et al., 2021). Associated with child differences, parents may need to manage difficult parenting events including tantrums and meltdowns (Ludlow et al., 2012), unusual responses to sensory stimuli (Grapel et al., 2015), verbal or physical aggression, damage to property, and self-injurious behaviours (Fodstad et al., 2012). Furthermore, children may present with differences relating to their sleep and restricted eating (Baraskewich et al., 2021; Johnson et al., 2018). Parents of children who have increased care needs are known to be at greater risk of unemployment and financial stress (Blackwell, 2024; Liao & Li, 2020; Witt et al., 2011).

Sociocultural influences may further influence parental mental health, where associative stigma and social isolation from friends and family, due to their child's autism-related behaviours, is linked to significantly higher parental psychological distress including shame, depression and anxiety (Deguchi et al., 2021; Kinnear et al., 2016; Wong et al., 2016). Children with autism are more likely to experience adverse interpersonal events including bullying, victimisation, social exclusion and

marginalisation in comparison to typically-developing peers (Maïano et al., 2016; Trundle et al., 2023).

#### 1.4 Stigma

Stigma is a phenomenon occurring within social contexts and is defined as having two main components: the recognition of difference, and subsequent devaluation, resulting in widespread social disapproval (Bos et al., 2013; Goffman, 1986). Stigma theories propose that the phenomenon originates from cognitive representations that perceivers hold about those with a stigmatised condition, and it may function to exploit or dominate the stigmatised persons, enforce social norms, or may be used as a method of disease avoidance (Bos et al., 2013; Link & Phelan, 2014). Forms of stigma are variable, but can manifest overtly as social rejection, aversion to interaction, stereotyping, and dehumanisation or depersonalisation of the stigmatised person (Bos et al., 2013; Frost, 2011). Stigma can also present more subtly through non-verbal expressions of discomfort from the perceiver, resulting in tensions during interactions with the stigmatised person (Bos et al., 2013; Pescosolido & Martin, 2015). Since Goffman's (1986) stigma theory, there has been a growing body of diverse literature regarding the phenomenon, with notable overlaps with constructs such as prejudice. Bos et al. (2013) argue that stigma and prejudice are separate concepts, as stigma involves reactions to perceived negative deviance, whereas prejudice does not necessarily imply this.

Pryor and Reeder (2011) propose a model which suggests there are four inter-related manifestations of stigma: public stigma, self-stigma, stigma-by-association, and structural stigma. Public stigma is described as the “*springboard*” (Pryor & Reeder, 2011, p. 4) for other types of stigmas and incorporates cognitive, affective and behavioural elements. Negative stereotypes and commonly held beliefs about stigmatised conditions are theorised to invoke emotional reactions within the perceiver, such as anger, fear or disgust, resulting in them responding using behaviours already described above (Pryor & Reeder, 2011; Vogel et al., 2013). Self-stigma is understood to be derived from the awareness of public stigma related to an individual's condition, alongside enacted experiences of stigmatised treatment from other people, resulting in the internalisation of stigma (Vogel et al., 2013). This is evidenced to have a profound impact on an individual's self-concept and can lead to diminished self-worth and self-efficacy, and experiences of guilt and shame (Jahn et al., 2020; Wood et al., 2017).

Crucially, it is evidenced that public and self-stigma can adversely affect recovery attitudes, processes and outcomes for people experiencing psychological distress or with diagnosed mental illness (Chan et al., 2022). Stigma-by-association, also known as courtesy stigma (Goffman, 1986) arises from being connected to somebody with a stigmatised condition, where there may be potential for them to be perceived as somehow tainted or discredited as a result (Pryor et al., 2012; Pryor & Reeder, 2011). This can lead to individuals experiencing public and self-stigma and the subsequent impact of these, which has been defined elsewhere in family caregiver literature as 'affiliate stigma' (Mak & Cheung, 2008; Mikami et al., 2015; Shi et al., 2019). Finally, structural stigma represents the perpetuation of stigma through society's ideological systems and institutions (Bos et al., 2013; Hatzenbuehler, 2016). It can be perpetuated through laws and policies that may legitimise discrimination towards people with related stigmas, such as laws previously preventing gay marriage (Pryor & Reeder, 2011).

A body of literature has investigated stigma with PAC populations. Qualitative studies have highlighted that PAC recognise autism as a publicly stigmatised condition, which contributed to their dilemmas around whether to seek a diagnostic assessment for their child (Russell & Norwich, 2012). Parents' perceived lack of knowledge about autism has been linked with internalisation of stigma, where parents have questioned whether they were 'to blame' for their child's diagnosis (Salleh et al., 2022). A meta-synthesis of qualitative studies has documented several types of enacted stigmatisation experienced by PAC, including rude comments from others, avoidance or rejection by others, and overly hostile staring (Kinnear et al., 2016; Salleh et al., 2020). Affiliate stigma has been experienced by PAC within personal social circles, health, care and educational settings, and from members of the public, particularly during instances where their child's behaviour was deemed socially inappropriate (Gray, 1993; Liao et al., 2019). During these circumstances, PAC report experiences such as being labelled 'bad parents' (Broady et al., 2017), and self-stigma through embarrassment arising from their child's behaviour (Salleh et al., 2020). PAC have further highlighted the lack of support from health, care and educational settings as perpetuating these difficulties, which may be interpreted as structural stigma (Broady et al., 2017). Finally, PAC have described fears related to how their children will fare in social situations throughout their life, recognising the likelihood of public stigma (Russell & Norwich, 2012).



## 1.5 Shame

Shame is defined as an adaptive self-conscious emotion, that is universally experienced, particularly when an individual recognises that their personal characteristics or behaviour are perceived to be inappropriate, either within their broader situational context around other people, or at times when this may conflict with the individual's own morality, ethics or values (Gilbert, 2003; Tangney et al., 2004). It is theorised that shame is associated with an evolutionary drive relating to the competitive dynamics of life; to seek acceptance, connection and desire from others; and it is therefore linked to a threat-based system that alerts an individual when this is not the case (Gilbert, 2003).

When shame is experienced, it can drive a person to distance themselves from others to conceal the shame-inducing stimuli, to prevent distressing outcomes such as social exclusion, rejection and devaluation (Hultberg, 1987). Shame is often associated with guilt, but these two emotions are distinct from one another (Gilbert, 2003). Guilt may arise from a negative evaluation from a behaviour (e.g., *I said that wrong and it upset them*) which often fuels a person to take action to rectify the perceived problem. Alternatively, shame often becomes internalised to fuel self-blame and criticism (e.g., *I'm a bad person*), resulting in social distancing from others, which is understood as a protective mechanism (Gilbert, 2003).

Although shame is a universal emotional experience, it is increasingly recognised that it can mediate between adverse life events and symptoms of psychopathology (Cândea & Szentagotai, 2013; Lewis, 2019). For example, Pinto-Gouveia & Matos (2011) investigated the centrality of shame memories within a sample of 811 participants from the general population and found that these contributed to depression, anxiety and stress prediction. Shame is also recognised to be associated with further difficulties including obsessive compulsive disorder (Laving et al., 2023), post-traumatic stress (DeCou et al., 2023; López-Castro et al., 2019) and disordered eating (Bottera et al., 2020; Nechita et al., 2021). Furthermore, it is evidenced that self-criticism can mediate the relationship between the centrality of shame memories and psychopathologies, such as depression and paranoid beliefs (Pinto-Gouveia et al., 2013). Shame is also recognised as a key barrier that may deter people from accessing mental health services (Dunford & Granger, 2017; Khan et al., 2007). Shame-related behaviours are referenced as a reason for client non-disclosure and active disengagement during psychological therapy (Black et al., 2013; Hook &

Andrews, 2005). Therefore, it is argued that shame proneness and shame regulation hold important clinical implications as both predictors and potential mechanisms for change (Cândeia & Szentagotai, 2013).

Shame Resilience Theory (Brown, 2006) was developed through a grounded theory (Glaser et al., 1968) study regarding women's shame experiences, to determine the processes used to develop shame resilience. The theory uses a continuum, where at one side participants felt trapped, powerless, and isolated. On the other side, the concept of shame resilience is theorised to involve four components: empathy, connection, power, and freedom. Interestingly, it is reasonable to argue that these shame resilience components appear to map onto some of the key attributes of compassion, as defined by Gilbert (2009). Quantitative research has since evidenced empirical support for the assumptions of this theory by indicating that critical-awareness and self-compassion were significant individual predictors of shame (Bendure, 2014). This highlights the potential efficacy of using compassion focused interventions to foster shame resilience in shame-prone populations. Given the literature evidencing the prominence of affiliate stigma and higher mental health pathology in the PAC population, it is reasonable to identify PAC as a potential shame-prone population.

## **1.6 Current Policy and Guidelines for the Support of Parents of Autistic Children**

NICE details clinical guidelines to assist clinicians in decision-making processes relating to treating specific conditions or working with particular client groups. The guidelines are developed from systematic reviews of the evidence in the current literature alongside explicit considerations around cost effectiveness. Two NICE (2017, 2021b) publications present specific guidelines for the referral, assessment, treatment and management of autistic children and young people. Although the acknowledgement of parental mental health is not explicitly detailed in either guideline, subsection 1.2 of NICE (2021b) Clinical Guideline 170 provides recommendations around offering families an assessment of their own needs, including personal, social, and emotional support, practical support in their caring role, and plans for future care for the child. Where needs are identified, NICE recommends that clinicians discuss the help available locally and offer parents information, advice, training, and support if parents require support with the care of a child, or if they are involved with the delivery of an intervention with their child in collaboration with health and social care. However,

it does not specify best practice support recommendations if this is required for parents. The guideline also recommends that clinicians inform parents of their rights to request a carers assessment, short breaks, and respite.

### **1.7 Guided Self-Help Interventions**

Guided self-help interventions involve an individual working through a self-help workbook or online course, with the support of a therapist (NHS, 2022). Guided support can be facilitated in several ways including telephone contact (Potter et al., 2021) or via email (Finn & Schoech, 2014) and for differing lengths of time, depending on the function of the guided support element (Finn & Schoech, 2014). Systematic reviews and meta-analyses provide evidence that guided self-help can have comparable effects to face-to-face psychotherapy for anxiety and depression (Cuijpers et al., 2010; Moshe et al., 2021), although included study modalities are heavily dominated by cognitive behavioural therapy (CBT). Furthermore, there is tentative evidence to suggest that mindfulness and acceptance can be effectively cultivated via self-help interventions (Cavanagh et al., 2014; Taylor et al., 2021) although the current body of evidence is notably small.

Currently, the vast majority of CFT randomised controlled trials (RCT) are facilitated as group interventions rather than guided and unguided self-help, although tentative evidence recognised within a systematic review highlighted that brief and self-help compassion interventions can show promise when used within complex clinical populations (Craig et al., 2020). Further brief compassion-based interventions have shown promising results (Kirby et al., 2023) highlighting the need to further this evidence base in order to develop preventative mental health interventions that can become accessible to a broader population. One concern highlighted amongst reviews of self-help interventions relates to high attrition rates (Hermes et al., 2019). The addition of guided support and choice of interaction for this element is noted to positively influence retention (Day & Sanders, 2018; Wojtowicz et al., 2013).

### **1.8 Definition of Compassion**

The concept of compassion has been grounded within multiple spiritual and philosophical traditions for over a thousand years but has recently become a major

focus of international psychological research in prosocial behaviour (Feldman & Kuyken, 2011; Gilbert et al., 2017). However, there are contradictions in how the concept is defined (Gilbert, 2017; Matos, Duarte, et al., 2022), with several major definitions provided within the literature (Strauss et al., 2016).

An evolutionary-focused model by the founder of Compassion Focused Therapy (CFT) conceptualises compassion as a prosocial caring motivation with two key components: “*the sensitivity to suffering in self and others, with a commitment to try to alleviate and prevent it*” (Gilbert, 2014, p. 19). Similarly, Kanov et al. (2004) define compassion in the context of work organisations as holding three subprocesses: “*noticing another’s pain, experiencing an emotional reaction to the pain, and acting in response to the pain*” (Kanov et al., 2004, p. 808). Gilbert (2009) has further identified six key attributes of compassion: sympathy, empathy, distress tolerance, non-judgement, sensitivity, and care for well-being.

A major review of compassion definitions by Strauss et al. (2016) supplemented their own definition by viewing it as a multidimensional construct involving cognitive, affective and behavioural processes with five key elements: recognition of suffering; understanding suffering as a universal human experience; connecting with distress and feeling empathy for the person suffering; tolerating any uncomfortable feelings aroused in response to the person suffering to maintain an open and accepting stance; and motivation to act to alleviate or prevent suffering. In summary, despite apparent nuances within each definition, all conceptualise compassion as a caring motivation that incorporates a range of competences to support its execution, which may include sensitivity, empathy, wisdom, openness, courage, non-judgement, and distress tolerance, plus many more (Feldman & Kuyken, 2011; Gilbert, 2000b; Gilbert et al., 2017).

As a caring motivation, compassion is understood as a dynamic intra- and interpersonal process occurring within social interactional contexts (Matos, Duarte, et al., 2022). Gilbert (2017) suggests that the flow of compassion can be directed in three different ways; directing compassion towards others, receiving compassion from others, and directing compassion towards the self. Further work to define self-compassion was undertaken by Neff (2003a, 2003b) who conceptualises this as having three key elements:

- (a) *self-kindness—extending kindness and understanding to oneself rather than harsh judgment and self-criticism,*
- (b) *common humanity—seeing one’s*

*experiences as part of the larger human experience rather than seeing them as separating and isolating, and (c) mindfulness—holding one’s painful thoughts and feelings in balanced awareness rather than over-identifying with them (Neff, 2003b, p. 89).*

Studies have explored the interrelationship between self-compassion and compassion to others, showing variable results with significant heterogeneity (López et al., 2018; Neff & Pommier, 2013; Sahdra et al., 2023). This may evidence the notion that individuals may experience high levels of compassion to others but a reduced ability to be compassionate towards themselves, or vice versa. However, this could also suggest weaknesses in the correlational study designs, the definitions of each construct, or limitations of the compassion measures utilised, such as the Self Compassion Scale as developed by Neff (2003; Strauss et al., 2016; Williams et al., 2014).

### **1.9 Influences of Parental Compassion for Parents and their Autistic Child/ren**

A wealth of benefits associated with compassion are increasingly recognised within PAC literature. Self-compassion has been positively associated with life satisfaction, hope, and goal reengagement, and negatively associated with depression and parental stress amongst PAC (Neff & Faso, 2015). Interestingly, self-compassion is deemed a stronger predictor of PAC parental stress and well-being levels than child behavioural-emotional problem severity (Shenaar-Golan et al., 2021), and is identified as a moderator in the association between affiliate stigma and psychological distress amongst PAC (Wong et al., 2016). These factors highlight the potential role of self-compassion as a protective factor to improve mental health within this population, as echoed by Torbet et al. (2019), and reflects the theoretical assumptions of CFT, where compassion is understood as central to the process of recovery from psychopathology (Gilbert, 2003, 2010).

Crucially, the positive benefits related to compassion are evidenced to include parenting styles, which may result in subsequent positive influences for their children. The ability to be self-compassionate in response to challenges is understood to be tied to the attachment behavioural system (Gilbert & Procter, 2006; Lathren et al., 2020), and is associated with secure attachment styles (Beduna & Perrone-McGovern, 2019; Lathren et al., 2020; Neff & McGehee, 2010) and is negatively associated with insecure

attachment styles, categorised by anxiety or avoidance (Lathren et al., 2020; Raque-Bogdan et al., 2011). Furthermore, lower levels of child self-compassion have been associated with perceived unsupportive parenting experiences, such as high parental rejection and low parental warmth (Pepping et al., 2015), emotional abuse (Ross et al., 2019), invalidation (Westphal et al., 2016), and controlling parenting styles (Kaufmann et al., 2023). Similarly, these parenting styles are also linked to lower levels of parental self-compassion, whereas high parental self-compassion is associated with more facilitative parenting styles (Kirby, Grzazek, et al., 2019; Miller et al., 2015). This may be explained by considering the key attributes of compassion that are directly applicable to parenting: to be sensitive to a child's needs, and to respond appropriately (Kirby, 2019). Affiliative motivational systems accessed through compassion are theorised to be associated with caring-nurturance and parental investment, which may help to facilitate the attachment system (Fogel et al., 1986; Kirby, 2019). Furthermore, affect regulation developed through compassion-based interventions may provide parents with the skills to recognise when they are influenced to react towards challenging parenting events in an automatic, threat-based and maladaptive way, to enable more opportunities to respond to such events using a more authoritative parenting style (Kirby, 2019). This further highlights the potential value of compassion cultivation with parents, as this could strengthen parent-child attachment relationships, which could positively influence child well-being, although this hypothesis requires further investigation as a future research direction.

### **1.10 Theories Underpinning Compassion Focused Therapy (CFT)**

CFT was founded by Paul Gilbert (2000) partially in response to the observations that many people attending traditional psychotherapies, such as CBT, presented with high levels of shame and self-criticism. This appeared to exacerbate difficulties around their abilities to generate empathetic and self-supportive inner voices, which inadvertently prevented true engagement in many of the therapeutic processes within traditional therapies, thus limiting intervention effectiveness (Rector et al., 2000). CFT was based on the evolutionary model of social mentality theory (Gilbert, 2000b, 2016), which suggests that most aspects of internal and external human behaviours, including thoughts, emotional states, and physiological responses, are the result of our psyche comprising of different motivational systems and strategies, which ultimately aim to support the survival and propagation of humanity. These motivational

strategies, such as caring, attacking, or submitting, work to support humans to seek required resources such as food and shelter, to seek proximity with social groups for protection, nurture, and sexual opportunities, and to detect and prevent possible threats to life (Gilbert, 2000b, 2014b). It is theorised that individuals often experience internal conflicts, which arise from opposed or conflicted evolved strategies interacting with each other during a situation. Gilbert (2000b) provides an example of a common internal conflict; when a person perceives they have failed, they could become angry and self-criticise. This anger might activate an internal threat signal, which may subsequently precipitate submissive strategies such as lowered mood or shame whilst unprotected from their self-attack.

CFT suggests that humans can experience unhelpful patterns of thinking due to the evolution of the human brain's processing abilities, now termed a 'tricky brain' (Gilbert, 2014b). It suggests that humans evolved a range of higher-level cognitive competencies which create a socially contextualised sense of self (Gilbert, 2014b). These additions are referred to as parts of our 'new brain' within the CFT model. However, the theory suggests that the more primitive motivational systems, as described above and referred to as the 'old brain', can cause the brain to become easily triggered whilst sensing danger arising from 'new brain' activity, leading to mental health difficulties and potentially destructive behaviours (Gilbert, 2014b; Tirch & Gilbert, 2015). For example, should an individual use their new brain's ability to recall a memory involving a feared stimulus, their old brain may become triggered, resulting in a threat response within the present moment, in the absence of the feared stimulus. These evolutionary concepts are shared as psychoeducation during therapy, to develop clients' awareness about the universality of human suffering, and to de-centre from the contents and processes of their minds, to reduce the influence of shame and self-criticism (Tirch & Gilbert, 2015). Unhelpful thinking loops can be investigated during the therapeutic process to formulate existing patterns of distress whilst de-shaming client experiences, building on CBT approaches to support clients' learning regarding thought and affect monitoring and acceptance (Gilbert & Procter, 2006).

The theory also suggests that humans have three main types of emotion regulation systems that have evolved from our motivational systems and invoke differing cognitive, affective and behavioural responses (Gilbert & Choden, 2015). The 'threat' system enables individuals to detect and respond to threats in a self-protective manner, and is associated with emotions including fear, anger, jealousy and disgust.

The 'drive' system supports resource-seeking by helping individuals to take pleasure in securing important resources to support survival, and is associated with emotions such as excitement or happiness. Finally, the 'soothe' system promotes a sense of safety, calmness and content, and is often linked to experiences of acceptance, kindness and compassion (Gilbert & Simos, 2022; Kolts, 2016). It is evidenced that the latter emotion system may hold a role in the evolution of attachment styles experienced by humans (Bell, 2001; Bowlby, 1969, 1973, 1980). Each emotion system and their related motives are associated with different patterns of attention, affect, thinking and reasoning, mental imagery, and behaviour (Kolts, 2016). Importantly, people are often caught between their drive and threat systems due to the competitive social mentality perpetuated through societal motivators (Gilbert, 2010) which can often result in shame and self-criticism. CFT instead focuses on the cultivation of compassion to enable individuals to access their soothe system, to bring balance to their time spent within different emotion systems, and to activate a caregiving mentality towards themselves and others (Gilbert & Simos, 2022).

### **1.11 Compassionate Mind Training (CMT)**

CMT is understood as a key part of the CFT process (Gilbert & Procter, 2006), although it can be delivered as a standalone process to non-clinical populations (Halamová et al., 2020). The purpose of CMT is to alter an individual's orientation to their relationships with self and others, rather than holding a specific focus on targeting core beliefs as seen in CBT (Gilbert & Procter, 2006; Matos et al., 2018; Matos, Duarte, et al., 2022). To facilitate this, CMT focuses on understanding and adjusting the threat-based, dominating, and self-attacking strategies often used by individuals experiencing distress, to instead focus on cultivating an alternative compassionate, wise, strong, and caring approach to move toward and alleviate distress (Gilbert, 2010, 2016; Gilbert & Procter, 2006). CMT can be facilitated within a group (Gilbert & Procter, 2006; Irons & Heriot-Maitland, 2021), through guided self-help (Sommers-Spijkerman et al., 2018) and online formats (McEwan & Gilbert, 2016) with differing levels of supervision, from none (McEwan & Gilbert, 2016) to direct therapist input (Matos, Duarte, Duarte, et al., 2017). The approach is empirically supported to promote psychological well-being when delivered as a brief intervention over 2-weeks (Kirby et al., 2023; Matos, Duarte, Duarte, et al., 2017) and longer group training programmes of 8-weeks (Matos et al., 2022; Savari et al., 2021).



In practice, CMT involves two key elements: psychoeducational content and experiential practice (Gilbert & Procter, 2006). Key psychoeducational components already described in section 1.10 are explored with the individual. CMT also incorporates several experiential practices, using a range of physiological, psychological, imaginal, and body-based practices such as practicing a compassionate body posture, soothing rhythm breathing, mindfulness, compassion-based imagery and compassionate letter writing (Matos, Duarte, Duarte, et al., 2017). These experiential exercises aim to train individuals to develop competencies that facilitate grounding, mindfulness, and using a compassionate focus and orientation to self or others (Matos, Duarte, Duarte, et al., 2017). Physiological exercises such as soothing rhythm breathing are evidenced to activate the parasympathetic nervous system and improve heart rate variability (Lin et al., 2014), which is recognised to have positive implications for stress reduction and health (Thayer et al., 2012) and therefore may be valuable for the PAC population, who are evidenced to experience significant parental stress. There are several compassion-based imagery practices (Kolts, 2016; Tirch & Gilbert, 2015) within CMT, including imagining a compassionate image directing compassion towards others or the self, and bringing to mind and cultivating compassionate motives and a self-identity (Gilbert, 2010; Gilbert & Choden, 2015; Gilbert & Simos, 2022; Kirby et al., 2023; Matos, Duarte, Duarte, et al., 2017). The apparent intervention efficacy evidenced within a range of different population groups, alongside the flexibility in how a CMT intervention can be facilitated, are highlighted as key strengths that further supported the justification for why this approach should be investigated further in the present study, to understand whether this could be applicable for PAC.

### **1.12 Evidence Base for Compassion-Based Interventions**

Since CFT was developed around two decades ago, there is a rapidly growing evidence base in support of compassion-based intervention treatment efficacy. Leaviss and Uttley (2015) conducted the first early systematic review to determine the psychotherapeutic benefits of CFT and concluded that the intervention showed promise for use with individuals experiencing mood disorders and self-criticism, where it may be more effective than no treatment or treatment as usual groups. The review included fourteen studies, where only three were RCTs. This likely reflected the relatively young age of the novel intervention, where smaller scale feasibility studies should be facilitated prior to larger scale RCTs as per intervention development practice

guidelines (Skivington et al., 2021b). However, this meant there was insufficient high-quality evidence to demonstrate that CFT was more effective than current standard treatments. Since then, further systematic reviews and meta-analyses have continued to demonstrate empirical support towards the efficacy of compassion-based interventions with a diverse range of populations (Ferrari et al., 2019; Kemp et al., 2022; Kirby et al., 2017; Millard et al., 2023; Wilson et al., 2019). Notably, as the research interest regarding compassion interventions has rapidly grown, Kirby et al. (2017) listed a further five empirically supported interventions that focus on compassion cultivation: Mindful Self-Compassion (Neff & Germer, 2013), Compassion Cultivation Training (Goldin & Jazaieri, 2017), Cognitively-Based Compassion Training (Pace et al., 2009), Cultivating Emotional Balance (Kemeny et al., 2012), and Loving-Kindness and Compassion Meditations (Hofmann et al., 2011).

### **1.13 Detailed Critique of Compassion-Based Intervention Studies with Parents of Autistic Children**

Fernandez-Carriba et al. (2019) facilitated an in-person Cognitively Based Compassion Training group with 15 parents, facilitated for two-hours over an 8-week period. Promising findings were reported by the authors, including improved acceptance of their child's condition, empathetic concern, parent-child relationships and cognitive flexibility. Furthermore, parental stress and child 'symptoms' were reported to have significantly reduced. However, the overall intervention uptake was low ( $n=16$ ), in comparison to parent expressions of interest ( $n>50$ ) prior to invitation to an informational session about the intervention. The authors did not collect data to explore the low uptake but recognised the possibility that intervention burden influenced participant disengagement and shared that exit comments from four participants that had discontinued midway through the intervention had attributed this to managing competing demands (e.g., scheduling, transportation, childcare arrangements). Notably, the intervention content was standardised and therefore not specific to PAC. From the description of the content provided by the authors, it did not appear that the concept of parenthood was recognised throughout the intervention. It may be argued that the lack of intervention adaptation to the parents' context may have reduced participant engagement, as it is recognised that the replication of standardised interventions is less likely to produce positive effects than adapted interventions with a better balance between intervention and context (Moore et al., 2021).

A brief intervention programme “*based on mindfulness and self-compassion and with cognitive-behavioural and emotional regulation components*” (Rojas-Torres et al., 2021, p. 13) was piloted with 10 PAC. To develop the intervention, the authors followed a Mindfulness Based Stress Reduction programme structure, which they integrated with aspects of Mindful Self-Compassion training and psychoeducational content, developed from their perceived needs of PAC. The intervention involved eight weekly face-to-face group sessions lasting 90 minutes. Sessions were divided into two parts; the first involved training on a mindfulness exercise, followed by psychoeducation about autism (example topics included ‘causes of autism’, ‘intervention methods in autism’, ‘access to work for autism’). Parents were instructed to engage in daily practices at home, which was hypothesised to take between 15 to 30 minutes per day. The authors concluded that stress and anxiety reduced following the intervention, and mindful attention awareness increased.

Several significant limitations were not considered by Rojas-Torres et al. (2021). Firstly, there was no reference to stakeholder engagement throughout the adaptation process, and their rationale for the psychoeducational topics chosen for discussion during each week of the programme was unclear. The authors did not provide information about quality checking for theoretical coherence after integrating intervention approaches and psychoeducational content. The multi-faceted nature of the intervention increases the complexity in deciphering the mechanism of change that influenced the outcomes. Notably, although the intervention was advertised as a compassion-based training programme, compassion was only referenced in the eighth and final session of the programme content.

#### **1.14 Definition of Complex Interventions**

The National Institute of Health Research (NIHR) and Medical Research Council (MRC; Skivington et al., 2021b) have recently updated their definition for complex interventions, as follows:

*“An intervention is conceived to be complex either (1) because of the characteristics of the intervention itself, for example multiple components or mechanisms of change, and/or (2) because how the intervention generates outcomes is dependent on exogenous factors, including the characteristics of*

*recipients, and/or the context or system within which it is implemented.”*  
(Skivington et al., 2021, p. xxi)

### **1.15 Definition of Feasibility Studies within Intervention Research**

After recognising the diverse views around how feasibility and pilot studies are defined in research literature, Eldridge et al. (2016) developed a conceptual framework to provide structure to the definitions for feasibility and pilot studies in preparation for RCTs. A Delphi study supported the conceptual framework development, which was later validated through subsequent systematic literature review and an international expert consensus meeting. It recognises the importance of feasibility research prior to main RCTs. It further suggests that all pilot studies are considered feasibility studies, but that some feasibility studies may not involve the pilot testing of an intervention. Instead, the framework recognises three variations of feasibility studies:

1. Randomised pilot study, where future aspects of a RCT, including the randomisation of participants to an intervention or control group, is conducted on a smaller scale.

2. Non-randomised pilot studies, where an intervention is tested on a smaller scale without randomisation of participants. This may include pilot studies with or without a control group, such as single case series research.

3. Other feasibility studies, where investigators aim to answer research questions around the feasibility of a future aspect of the intervention to be tested, but the intervention is not implemented for evaluation through pilot testing. This may include surveys, interviews or focus groups with key stakeholders to ascertain the acceptability of a new intervention, or to plan a protocol for implementation, evaluation, and refinement.

It was acknowledged that feasibility studies within the third category appeared more rarely in research literature, although it is possible that these were not always labelled by research authors as feasibility studies due to the absence of a pilot testing element, due to the prior lack of definition for feasibility research. The present research was developed to answer research questions related to anticipated feasibility, much alike this third category.

## **1.16 Review of Intervention Development Frameworks**

The theoretically-informed and carefully planned development or adaptation of complex interventions is necessary, to increase the chance that an intervention is likely to be effective during later implementation, evaluation, and promotion to the general population (O’Cathain et al., 2019; Wight et al., 2016). Interventions that are poorly designed can hold significant ethical and economical risks, including the possibility that infeasible, flawed, or ineffective interventions are prematurely implemented in everyday practice, or cause a significant waste of public resources through premature testing within large scale evaluation trials (Bleijenberg et al., 2018; Wight et al., 2016). Therefore, it is imperative that time is spent to carefully consider earlier stages of intervention design and adaptation. Several frameworks for the adaptation of evidence-based interventions exist, which can support developers to consider how to best approach adaptation to enhance clinical outcomes, acceptability and feasibility for the target population, whilst preserving mechanisms of change and theoretical coherence.

### ***1.16.1 Guidance for Developing and Testing Complex Interventions***

Although it is increasingly recognised that adapting and implementing interventions within new contexts is likely to be more efficient than developing new interventions (Moore et al., 2021), a subsequent demand for adaptation frameworks has recently risen from the potential tension observed between intervention fidelity and contextual fit, which are both recognised as factors that influence the associated outcomes from an intervention (Escoffery et al., 2019; Harn et al., 2013; Pérez et al., 2015). An initial large-scale scoping study of frameworks for adapting public health interventions (Escoffery et al., 2019) found 13 adaptation frameworks with 11 common steps, including an assessment of the community; understanding and selecting an appropriate evidence-based intervention; consulting experts and stakeholders; choosing and facilitating required adaptations; training staff and testing the adapted materials; and implementing and evaluating the adapted intervention.

Since this review, several further widely cited frameworks have been created or updated to include intervention adaptation guidance. The MRC and NIHR have recently updated their internationally renowned framework for the development and evaluation of complex interventions (Craig et al., 2008; O’Cathain et al., 2019; Skivington et al., 2021b, 2021a). The current framework (Skivington et al., 2021b) indicates four key

elements of complex intervention research; intervention development or identification (including adaptation); feasibility; implementation; and evaluation. Rather than a staged approach, the guidance instead emphasises that intervention development should occur as a non-linear and iterative process. It highlights the importance of considering six core elements during each phase of the research process, as each may indicate the need for further work in the same or a different phase. Core elements include consideration of context; development, refinement and testing of programme theory; stakeholder engagement; identification of key uncertainties; refining the intervention; and economic considerations. Skivington et al.'s (2021a, 2021b) framework supported the current authors' considerations during the identification process for an existing intervention, through reviewing psychological literature to better understand the anticipated contextual influences, environment, and psychological distress experienced by PAC. This involved a review of the literature, as documented throughout the journal paper and extended introduction, and a further systematic literature review to determine the effectiveness of compassion-based interventions for parents (Kemp et al., 2022). However, the framework provided limited detail regarding how an intervention adaptation process for public health interventions should be practically facilitated, so further adaptation-specific frameworks were considered by the authors and compared to the MRC/NIHR framework.

The Adapting interventions to new contexts guidance (ADAPT; Moore et al., 2021) is consensus-informed through a systematic review of existing guidance, a scoping review of published adaptation studies, qualitative interviews with key stakeholders, expert panel involvement, and a three round Delphi consensus-making study. The guidance produced was specifically created to promote better fit between intervention and context, to increase treatment efficacy. The guidance involves a process model incorporating four stages of adaptation, which largely map onto the four phases within the MRC/NIHR framework, but provide additional prompts to consider intervention-context fit, feasibility, intervention effectiveness and cost effectiveness as potential outcomes at each stage, which are listed below:

***Step 1: Assess rationale for intervention and consider intervention-context fit of existing interventions.***

***Step 2: Plan for and undertake adaptations.***

***Step 3: Plan for and undertake piloting and evaluation***

**Step 4: Implement and maintain adapted intervention at scale** (Moore et al., 2021, p. 4).

Crucially, ADAPT emphasises the importance of forming an adaptation team of diverse stakeholders prior to commencing step one of their process model, echoing the need for stakeholder involvement, including experts by experience, which is emphasised in other guidance frameworks. Despite this, a systematic review conducted to create a taxonomy of intervention development approaches for healthcare found that patient and public involvement within intervention development or adaptation studies was notably absent within included studies (O’Cathain et al., 2019).

Finally, during the course of the present study, a further pragmatic method for intervention adaptation was published, termed Making Optimal Decisions for Intervention Flexibility during Implementation (MODIFI; Brewer et al., 2024). MODIFI was developed through a modified Delphi process, and is presented as a three-step method of focused techniques with prompts for the developers at each stage, briefly quoted below:

**Step 1: Learn about the users, local context, and intervention.**

**Step 2: Adapt the intervention.**

**Step 3: Evaluate the intervention** (Brewer et al., 2024, p. 1)

Although MODIFI was published after the research process for the present study had concluded, it is recognised that the present study has largely followed steps one and two through conducting adaptations via learning about PAC, their context and the intervention through a prior systematic literature review of compassion-based interventions with parents (Kemp et al., 2022) and the further literature review and findings documented in the present report. This framework provides further justification for the present study design and procedure. Although MODIFI does not incorporate all potential techniques for adaptation as other frameworks attempt to do, this is arguably viewed as a strength to aid decisiveness and rapid assessment for developers working in applied settings with limited time and resources.

### **1.16.2 Guidance for Implementing and Reporting Adaptations of Existing Evidence-Based Interventions**

Inconsistent reporting of adaptations in the literature has led to uncertainty regarding the impact of adaptations on intervention outcomes (Brownson et al., 2017). Subsequently, there have been calls to develop a framework to facilitate the standardisation of publications that report adaptations to evidence-based interventions. As a result, the Framework for Reporting Adaptations and Modifications-Expanded (FRAME; Stirman et al., 2013, 2019) was developed as an evidence-based framework for characterising modifications to evidence-based interventions. It was developed from multifaceted data analyses via literature review, qualitative interviews, and a refinement process through multiple stakeholders (Stirman et al., 2019). The FRAME includes specific aspects regarding when, how and why an adaptation was facilitated, who participated in the decision to adapt the intervention, and the goal for adaptation. In comparison to other characterisation frameworks (e.g., Hall et al., 2017), FRAME provides thorough guidance on reporting of culturally responsive adaptations, which was desired in the present research to detail PAC cultural factors and contextual fit.

A further critique regarding all above frameworks is that they do not provide guidance around how decisions to proceed with adaptations are considered by the research team. The Model for Adaptation Design and Impact (MADI; Kirk et al., 2020) is an explanatory model that was developed to promote the systematic consideration of the intended and unintended impacts of adaptations on intervention outcomes. The model was created following the review, consolidation and refinement of ADAPT and FRAME (Moore et al., 2021; Stirman et al., 2019) and one intervention-implementation framework (Proctor et al., 2011). It underwent testing through qualitative coding of adaptations made in a prior study to arrange constructs from the existing frameworks into the MADI to detail adaptation characteristics, potential moderators or mediators of the adaptation impact on the intervention's outcomes, and the intended and unintended impact of the adaptation. To the researcher's current knowledge, the MADI is the only adaptation framework that moves beyond adaptation classification and can be prospectively applied to consider the anticipated impact of adaptations prior to future feasibility testing.



## 1.17 Stakeholder Involvement in Public Mental Health Intervention Research

Stakeholder involvement in research has been defined as follows:

*“the involvement of public, patients, health professionals, service users, payers, and other decision makers, from the early stages of setting priorities and forming research questions through to the final stages of implementing and disseminating results”* (Byrne, 2019, p. 290)

‘Stakeholder’ is understood as an umbrella term that may involve seven classifications for stakeholder groups, including patients and the public, providers, purchasers, payers, policy makers, product makers, and principal investigators (Concannon et al., 2014). Involvement of people with lived experience and their carers during health service improvement was first established as a requirement by the National Health Service and Community Care Act (1990) and has since been emphasised as a requirement at national and local levels (Health and Care Act, 2022; National Health Service Act, 2006). Alongside this, there is a clear moral necessity to empower people to contribute to service delivery, in attempt to redistribute inherent power imbalances (Beresford, 2013). Experiential knowledge from experts with lived experience is also increasingly recognised as a valuable data source for healthcare research (Brand et al., 2023). The UK Public Involvement Standards Development Partnership (n.d.) now cite public involvement as best practice in health research, and provide six standards to be used with any approach to public involvement in research; namely inclusive opportunities; working together; support and learning; governance; communications; and impact.

Main rationales for involvement are that it produces better quality research (Gray-Burrows et al., 2018) and ensures that interventions are relevant to user needs to increase the likelihood of positive outcomes (World Health Organization, 2024). As already discussed in section 1.16, stakeholder involvement is also recommended by various intervention adaptation frameworks, although was previously rarely reported in published intervention development studies (O’Cathain et al., 2019). Involvement study designs appear variable in existing intervention development literature, from consensus-taking methods using nominal group technique or Delphi surveys (Gonçalves et al., 2023; McSharry et al., 2016) to qualitative investigations using interviews and focus groups (Duggleby et al., 2020; Marlow et al., 2023; O’Hara et al., 2017). Active stakeholder participation and influence amongst all stages of research can also vary from redirecting, co-producing, refining or confirming study aspects and

is evidenced to impact study feasibility, scope, quality and relevance (Maurer et al., 2022).

Key principles of successful involvement have been detailed by the National Collaborating Centre for Mental Health (2019) using a CARING acronym; Celebrate involvement; Adaptable; Resources; Influence of power; Needs-led; and Growth. Alongside this, a number of challenges are recognised regarding involvement in complex intervention development research, relating to perceived inequality or power imbalances, inflexibility in meeting arrangements, communication breakdowns between stakeholders, and perceived role ambiguities (Skovlund et al., 2024), evidencing the complexity of planning involvement opportunities and the need to consider this carefully.

### **1.18 Further Rationale**

Following best practice guidelines for intervention development and adaptation, it is imperative that initial adaptation phases are duly considered (Moore et al., 2021; Skivington et al., 2021a). This could minimise potential harm to future study participants arising from issues such as mismatch between intervention materials and recipients, inaccessibility, or over-prescription (Papworth et al., 2015), to thus mitigate unforeseen factors that may limit the effectiveness of a guided self-help CFT intervention with PAC. This phase is warranted to support the planning for further evaluation and implementation phases for an intervention through pilot testing and future RCT. A stakeholder-informed adaptation process is required, following best practice for research and intervention development, and particularly because the intervention will involve heavy reliance on PAC engagement through self-directed practice. Therefore, it is important that relevant stakeholders, including PAC, are consulted at all stages of intervention development, to enhance the anticipated relevance, usability and acceptability of the intervention in future practice.

The adaptation of an existing CMT resource for parents was felt to be required to increase specificity for PAC, as it is recognised that PAC experience unique differences and challenges within their parenting role. Differences are thought to be related to their child/ren's differences associated with autism, alongside wider systemic differences related to navigating educational, health, and social care services, and the influence of affiliate stigma, as discussed in sections 1.3 and 1.4. It is evidenced that

enhancing intervention-context fit through the adaptation of evidence-based interventions to increase specificity regarding recipients' cultural backgrounds (e.g., parenting an autistic child) can enhance recipient engagement with an intervention, acceptance of an intervention, and satisfaction regarding the intervention, which may further enhance intervention outcomes (WHO, 2024). There is a lack of published CFT interventions for parents, likely due to the early stage of this emerging evidence base. The existing CMT resource that was provided by Dr James Kirby was viewed to have potentially inappropriate content for this sub-population of parents, such as detailing neurotypical developmental milestones that may not be relevant to autistic children, and a lack of discussion around the nuances of parenting an autistic child. Furthermore, the existing resource was developed as self-help material following a two-hour seminar and was provided as one large resource, with the assumption that participants already held existing knowledge regarding CMT due to the seminar, rather than this being formatted as a step-by-step intervention to be accessed by PAC who may not have existing prior knowledge of CMT.

The aim to create an adapted CFT resource for PAC should not be interpreted as an attempt to develop a 'best' format for PAC to engage in this therapeutic modality in comparison to existing group or in-person methods. Rather, it aims to provide an additional alternative method to access CFT, to address some of the barriers to service engagement that are evidenced to be experienced by this population. The creation of a PAC-focused CFT intervention using guided self-help methods would be the first of its kind to the best of the researcher's knowledge and could provide PAC with greater flexibility in how and when they engage with the intervention, as well as minimising potential financial burdens associated with travel costs and childcare arrangements when attending group therapies. Furthermore, guided self-help interventions may appear more palatable for many PAC who experience high levels of shame, self-criticism, or perceived stigmatisation, as it is reasonable to assume that these factors may further deter PAC from seeking mental health support.

In line with the NHS (2019) Long Term Plan, there is a need for further preventative mental health interventions to provide timely access to psychological support and reduce the pressures that currently burden mental health services nationally (NHS Confederation, 2022). Further PAC-specific well-being interventions are warranted, due to the observed poorer mental health outcomes in this population, and as current interventions are heavily focused on treatment of child behavioural

differences, rather than PAC mental health. It is evidenced that poor PAC mental health has detrimental consequences to their wider family systems, including their child/ren's development, further highlighting a need to further the evidence base related to effective well-being support for this population.

### **1.19 The Starting Resource**

An existing CMT workbook for parents was developed by The Compassionate Mind Research Group and used as material handed to parents following a brief two-hour CFT seminar intervention (Kirby et al., 2023). The workbook was fifty-five pages in total and aimed to be used by parents to review in their own time after attending the seminar. The content of the workbook was largely paragraphs of text, formatted using the Calibri (Body) font in size 11 with 1.5 line spacing. Diagrammatic representations were incorporated twice in the workbook to present the CFT emotion regulation systems diagram (Gilbert, 2010), and the patterns associated with a competitive versus caring social mentality. A brief introduction to the workbook was provided on page three. Pages five to 27 were designated to psychoeducational content separated into four 'parts' within the workbook. Pages 27 to 47 then provided written scripts for CMT exercises, and further tip sheets were supplied as appendices from pages 50 to 55. Further details for each section of the workbook are as follows:

Part one aimed to introduce parents to the theoretical background of CMT, presented as thirteen pages of text to read. The psychoeducation content included the provision of a definition of compassion with examples. The 'tricky brain' concept was shared by linking this to the theory of human evolution, to normalise the universality of human suffering by recognising how the 'new brain' and 'old brain' can inadvertently interact to stimulate ongoing distressing emotional states. Social mentality theory was used to explain how human motives and goals may influence the patterns of thinking and bodily sensations that an individual experiences, comparing a competitive social mentality to a caring social mentality. The three types of emotion regulation system (Drive-Threat-Soothe) were presented diagrammatically and with follow up explanations with examples. Parents were introduced to the concept of having 'mini-selves', which are driven by having different motives and emotional states and may hold one's attention and focus. An example of how an 'anxious self' might respond in a hypothetical scenario is provided, considering how this self might think about the event, what physical sensations it might notice, and how it might respond. Finally, the power

of attention is highlighted as a mechanism of change, through developing a mindful awareness of which 'mini self' is in the spotlight of our attention, to then make the deliberate choice to switch to a 'compassionate self'. Part one ends by explicitly recognising this as the aim of CMT.

Part two consisted of three pages, to share important information about being a parent and how this relates to compassion, whilst continually normalising the challenges of parenthood. The chapter provided reflections on the experience of parenting, how this may lead parents to shift into competitive or self-critical mindsets, and the subsequent impact on parental wellbeing. It listed variable expected developmental milestones for children and related this to their changes in care needs from their parent over time, including emotional co-regulation.

Part three was presented as three pages and focused on preparing the parent to practice the CMT exercises. The section provides an explanation of what is meant by compassionate imagery, and how parents can foster their compassionate self. Potential concerns were recognised and explored proactively, including instances where a parent may experience a 'wandering mind', or struggle to create 'clear pictures' in their mind, or have difficulty finding the time to practice.

Part four shared the CMT practices, including a one-page summary with instructions around how often to practice each of the exercises over a two-week period. Seven exercise scripts were included at the back of the workbook to support parents' engagement in CMT practices following the seminar. The first four exercises aimed to develop a base for compassion training through body and mind exercises; developing inner conditions for compassion development through posture; using facial expressions and voice tones; soothing rhythm breathing; and a mindfulness exercise. The final three exercises aimed to support parents to cultivate their compassionate selves through compassion training exercises; building and cultivating the compassionate self; directing the flow of compassion to others; and directing the flow of compassion to the self. Accompanying audio track recordings of each script being read aloud were provided to guide parents' practice.

## **2.0 Extended Methodology**

### **2.1 Epistemological Position**

Epistemological positions are characterised by a set of assumptions about the theory, nature, sources, and use of knowledge (Ormston et al., 2014; Willig, 2012). Importantly, such positions function to guide the project design, data collection, and interpretation, including the conceptualised relationship between the researcher and generated knowledge, so thus should be considered at the outset of project design (Chamberlain, 2015). Quantitative researchers may hold a position of positivism, where reality is understood as factual and an objective truth is uncoverable, which may be measurable and is unaffected by the research process (Willig, 2008). In such research, inductive reasoning may be used following data collection to generalise from empirical instances to general 'laws' or 'facts' in knowledge (Else-Quest & Hyde, 2016). Alternatively, qualitative researchers may uphold positions of interpretivism or constructionism, where greater emphasis is placed upon how reality becomes affected by the research process, such as how the researcher interprets or constructs meaning around the data gathered (Willig, 2008). As such, the product of research is understood to be subjective and aims to faithfully represent participants' meanings, rather than aiming for generalisability to the mass population (Lune & Berg, 2017).

In contrast to committing to a particular epistemological position, some researchers argue for a position of pragmatism (Ormston et al., 2014; Seale et al., 2007). This approach focuses on the practical requirements of the research question, to dictate the best methods of data collection to be used. Pragmatists may approach research questions using singular or multi-methods to conduct research by aiming to broadly understand the phenomena under investigation, and therefore might be seen as effectively bridging the gap between epistemological positions. This position was particularly appealing for the present study aims which held a practical focus; to adapt a CFT resource into a guided self-help intervention for PAC.

### **2.2 Ethical Considerations**

As highlighted within the BPS (2021) Code of Human Research Ethics, it is of upmost importance for ethical considerations to be included throughout the research procedure as they are fundamental to quality psychological research.

### **2.2.1 Gaining Ethical Approval<sup>52</sup>**

The research was reviewed and approved by the University of Nottingham Mental Health and Clinical Neurosciences ethics committee (previously called the Division of Psychiatry and Psychology at time of application). Due to unforeseeable barriers during facilitation of the research, there were several changes to the original research design, which were considered through research supervision<sup>53</sup>. Ethical amendments for any changes to the research design were reviewed and approved by the ethics committee prior to the researcher deviating from the original approved procedure.

### **2.2.2 Obtaining Informed Consent**

Participant Information Sheets<sup>54</sup> provided to all potential participants were largely developed from a template from the University of Nottingham Mental Health and Clinical Neurosciences ethics committee, which is in line with the BPS (2021) Code of Human Research Ethics. This referenced the ethical approval number and provided comprehensive details around the purpose of the research, the participant eligibility criteria, the expected participant procedure, the potential benefits and costs of taking part in the research, information about data security, and contact details for the research team and ethics committee at the University of Nottingham. Furthermore, the Focus Group Guidelines document<sup>55</sup> was supplied for individuals to understand the ground rules for each meeting. Participants were informed that their participation was voluntary and that they had the right to withdraw at any stage of the research process, although they were informed that any contributions made within the audio-recorded focus group would not be technologically possible to remove from the dataset once this had taken place. All participants were provided at least one week to consider whether they would like to take part in the study. All were provided the opportunity to ask questions and discuss the project with the lead researcher via telephone, Microsoft Teams call or email, which supported a screening process for participant eligibility criteria and informed consent-taking. At the end of the screening process, participants

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<sup>52</sup> See Appendices C, D and E for ethical approval letters.

<sup>53</sup> See reflections in section 5.0 for further details regarding changes to the study design.

<sup>54</sup> See Appendices F and G for Participant Information Sheets for parents and clinical psychologists.

<sup>55</sup> See Appendix H for Focus Group Guidelines document.

were sent a consent form<sup>56</sup> to sign and return to the researcher via email to confirm their participation.

Following social media advertisement for PAC, the lead researcher experienced a barrage of emails often at similar timings. Each email was from separate addresses but followed a similar format, with limited information except the request to participate. This raised suspicion around the possibility of ingenuitous participants. The lead researcher followed the outlined recruitment protocol by sending the relevant information to each email. A response was often received within minutes, where individuals briefly stated that they fully understood the research, met eligibility criteria, and wanted to take part. This raised an ethical dilemma; the factors outlined above did not indicate that truly informed consent was obtained. This concern was raised to the research team. It was initially decided that respondents would be offered the opportunity to meet with the lead researcher to support the screening process prior to opting into the project, as per the screening protocol. Many individuals did not attend and did not respond to further emails. Several attendees were subsequently excluded from the research during screening as they did not meet eligibility criteria; unable to communicate effectively in the English language ( $n=2$ ), not currently residing in the United Kingdom ( $n=3$ ), not a parent of an autistic child ( $n=1$ ), unable to evidence informed consent ( $n=4$ ), and low researcher alliance during screening, characterised as conversing minimally and appearing disinterested in the project, which resulted in doubt around whether they would meaningfully engage within the focus group setting ( $n=5$ ).

The lead researcher reviewed recent literature around fraudulent participation in online research (O'Donnell et al., 2023; Sefcik et al., 2023; Woolfall, 2023) and subsequently did not respond to any further expressions of interest that indicated high risk of fraudulent respondents (i.e., similarities in timing of email received, vague wording, and email addresses used, as were recognised factors during the above screened out participants). A potential limitation is that this might have inadvertently screened out genuine participants. However, this approach was justified as a required precaution to safeguard the integrity of the research.

Three parents and one clinical psychologist opted into the research but later exercised their right to withdraw. Two further parents opted into the research but then

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<sup>56</sup> See Appendices I and J for Consent Forms for parents and clinical psychologists.



did not respond to their invitation to the focus groups. One parent briefly attended and left the first focus group without putting their camera on or unmuting themselves. They were contacted following the focus group and they provided brief written feedback and were sent their £10 Amazon voucher, like focus group attendees. They were thanked for their participation, but it was explained that they would not progress to the second focus group due to not meeting study criteria (ability to meaningfully contribute to the focus group discussion due to technological issues).

### ***2.2.3 Maintaining Confidentiality***

As previously outlined, all participants received information regarding how confidentiality is upheld throughout the research. All participants were informed that they could choose to join focus groups with their web camera turned on or off and could attend the meeting using a pseudonym. Within the Focus Group Guidelines, during the consent-taking process with the lead researcher, and at the start of each focus group meeting, participants were requested to adhere to confidentiality principles by keeping any information about the attendees and content discussed in each focus group confidential. However, all participants were informed that the research team could not guarantee that confidentiality principles would be upheld by other participants.

Participants were informed that focus groups would be audio recorded and transcribed verbatim by the lead researcher. Once data analysis was complete, the audio recordings were destroyed. Throughout transcription, any potentially identifiable information such as names, places or specific services were edited out of the transcript and replaced by generic labels such as [CITY] or [NAME]. Participants were labelled using pseudonyms in the transcripts, data analysis and research reports. The demographics questionnaires were completed anonymously, where participants were asked to input their own identification number to record and retain so that should they later decide to withdraw from the project, they could share this information to enable the researcher to delete their demographic information. All data collected were managed within the secure University of Nottingham OneDrive, conforming with General Data Protection Regulation (European Parliament and Council, 2016) and The Data Protection Act (2018). Data including identifiable information were stored in a separate area to transcripts, audio recordings, and demographic information.

#### **2.2.4 Prevention of Harm**

Focus group participants were encouraged to proactively consider their use of self-disclosure in the focus group setting. Parents were informed that they would not be directly questioned about their personal experiences by the facilitators. However, appropriate self-disclosure was welcomed if this felt pertinent to their feedback on the intervention materials and was comfortable to do so in the group context. The possible risk of psychological distress whilst discussing or hearing participant disclosures within the focus group were shared with parents, and they were made aware that the research team were unable to provide psychological support to participants at any stage of the research process. Instead, participants would be directed to signposting information within their Participant Information Sheet and Debrief Letter<sup>57</sup>, which listed national autism charities, parent support groups, and adult mental health support services. The focus group with clinical psychologists sought only the professional experiences of working therapeutically with parents and using compassion-based approaches, which felt low risk for potential psychological distress. Throughout all focus groups, participants were offered opportunities to take breaks and move around to prevent musculoskeletal issues and eyestrain whilst sitting in front of their computers for a long period.

Parents were offered a small monetary incentive (£10 Amazon gift voucher) to thank them for each time that they both reviewed the CMT workbook and engaged in the online focus group. This meant that if they engaged in both parent focus groups, they would receive two £10 vouchers in total. This was felt to appropriately reflect the time and effort required by the participants but was small enough to not be considered coercive. Within the Participant Information Sheet, information was provided around discussing with the lead researcher and their local job centre if there were concerns that acceptance of the voucher may impact their benefit entitlement.

Finally, the management of power imbalances were considered through focus group recruitment strategies and discussions. It was recognised that parent support group leaders, charity organisations and a BPS Division of Clinical Psychology Chair were alike to gatekeepers during recruitment, as ultimately, they decided whether and how to advertise the study. To manage this, the lead researcher ensured to liaise promptly with gatekeepers, providing study information including ethical clearance, and

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<sup>57</sup> See Appendix K for Debrief Letter for parents.

ensured to advertise the study in several ways to broaden the reach of the study advertisement through social media and snowball sampling techniques. Focus group moderation involved an active approach where other participants were brought into discussion to ensure that all participants had space to contribute, and all recommendations were welcomed thoughtfully by the moderators. During initial group contracting, participants were reminded that differing and diverse opinions would be respected by all attendees and valued by the research team as this provided unique insights and valuable data.

### **2.3 Defining Expertise Within the Participant Sample Criteria**

The term 'expert' can be defined as an individual representative of a group who is able to influence policy with either sufficient knowledge and experience (e.g., professional qualification and occupational or lived experience), or the power needed to instigate findings (Baker et al., 2006). Within consensus research, the labelling of involved stakeholders as 'experts' has been described by some as controversial, due to the practical difficulties regarding how to operationalise and quantitatively measure the amount of knowledge and experience of a subject matter that would be required for this to constitute an 'expert' standard (Caley et al., 2014; Nasa et al., 2021). Despite this, the label is often used within published consensus studies in healthcare research.

For the present study, the term 'expert' was not used within PAC and CP eligibility criteria, and participants were not referred to as experts within the journal or extended papers. Due to the significant heterogeneity of parenting experiences in autism, it would not be possible, nor appropriate, to attempt to operationalise PAC expertise, in order to attempt a differentiation between PAC that would be classed as an expert, and PAC that would not. The inclusion criteria for PAC participants instead focused on the nature of the relationship with the autistic child (i.e., seeking parents only, rather than broadening the criteria to include caregivers who may not hold a parental relationship with a child, such as teaching assistants). Furthermore, PAC's autistic child/ren were required to be under 18 years of age to meet eligibility criteria for the research, in order for participants provide their feedback whilst informed by their current experience. This was felt to potentially enhance the trustworthiness of the research findings, which considered the systemic factors influencing PAC's anticipated engagement with CMT-PAC. In contrast, it was felt that data provided by parents of adult autistic children could be less reliable due to the nature of retrospective recall,

and it was also recognised that the historic systemic context of their parenting experiences when their children were under 18 years of age, such as societal views regarding autism, may have differed to the societal context experienced by PAC in the present. Similarly, it did not feel possible to operationalise expertise regarding using CFT with PAC within the CP population, due to the inherent idiosyncrasies of parenting an autistic child, and so the term was not used to describe the CP participant sample.

The identification of “CFT experts” for the purpose of the present research involved the lead researcher searching the literature for prominent CFT clinicians in the field who have made multiple important contributions to CFT literature and practice. Contributions were operationalised as having published multiple highly cited peer reviewed academic journal papers related to CFT, alongside contributions to CFT manuals and textbooks, and the delivery of established CFT training courses, research groups, and conference presentations. Identified CFT clinicians were also required to have contributed to parent focussed CFT literature and/or training. Due to the current early stage of the PAC-specific CFT evidence base, it was not possible to further specify that only CFT clinicians who met the above criteria alongside expertise in the modality’s application with PAC could be approached by the research team. As all CPs involved during phase three and four of the research were CFT-trained and had already deemed CMT-PAC as theoretically coherent, it was decided that only two prominent experts from the field would be contacted. Consultation with the University of Nottingham Mental Health and Clinical Neurosciences ethics committee deemed that ethical approval was not required when requesting review of the CMT resource by CFT experts and documenting their feedback within the thesis.

## **2.4 Study Advertisement**

The lead researcher posted a study advertisement for PAC participants within online parent support groups on Facebook, which included those advertised as United Kingdom support groups for PAC, and countywide support groups for several locations including London, Liverpool, Lincolnshire, Derbyshire, Staffordshire, Leicestershire, and Nottinghamshire. Further attempts were made to recruit fathers through advertising within Facebook support groups that specified they were for this sub-population of PAC. The advertisement was also posted on Instagram, X and Reddit. Advertisements were re-posted weekly to improve visibility for members of the public. Various charity organisations that provided support to PAC were also approached via email and

telephone call to advertise the project, including Derbyshire Autism Services, National Autistic Society, Nottingham Autism Support Service, Autistic Nottingham, Relate Derby, Leicestershire Autistic Society, Lifeworks Staffordshire, Autism East Midlands, Rainbow PCF Derby, and Umbrella Derby. The study was further advertised within a Parent Carer Wellbeing newsletter published by Affinity Hub UK, and shared within the networks of all research team members with request that study details are passed to anybody that may be eligible to take part. Participants were encouraged to share the study information to those who may be eligible to take part.

CP recruitment was facilitated through networking of known professionals who had previously or were currently working within children's autism services. Contact was facilitated through LinkedIn direct messaging, WhatsApp messaging, email and in-person. CPs were requested to share the study information to those within their networks that might be interested and eligible to take part. The study advertisement was also sent to a BPS Division of Clinical Psychology chair for advertisement within their network.

## **2.5 Justification for Use of Online Focus Groups and Alternative Methods Considered**

Qualitative research can be used to support stakeholder-informed intervention adaptation processes to enhance the feasibility, acceptability and positive intervention outcomes during future trials within a new target population (Duggleby et al., 2020). Focus groups are defined as a multi-person synergistic interview, where group interaction is explicitly used to generate data on a topic defined by the researcher (Finch et al., 2014; Morgan, 1995; Stewart & Shamdasani, 2015). Focus groups are used across a variety of fields, initially within applied marketing (Calder, 1977) and this since broadened to include communication, education, healthcare research, and political science (Delli Carpini & Williams, 1994; Morgan, 1995). Rather than each attendee being asked each question individually by the moderator, participants are instead supported to discuss topics in a group setting, ask each other questions and reflect on each other's perceptions and insights. This approach may increase data richness as participant views may have been explored more easily through interactions and gentle questioning between group members, rather than during an individual interview setting (Acocella, 2012). Alongside the obvious practical advantage on timing and resources needed in comparison to facilitating and transcribing individual

interviews, focus groups are understood to be a useful method for fostering creative thinking and solution generation for a research question (Kitzinger, 1995). As the research aimed to adapt an evidence-based intervention for PAC using stakeholder feedback, this attracted the lead researcher to the focus group method. This method could involve live decision-making and generation of a consensus view, to inform the intervention refinement protocol. However, it is recognised that there are potential disadvantages associated with tensions within the multi-person component. Interactional processes between group members may influence the risk of groupthink, where members may censor their views to conform with the perceived norms or opinions held within the group, unknowingly jeopardising the research fidelity (Côté-Arsenault & Morrison-Beedy, 2005). Further factors may affect group interactions including the possibility of dominant voices within the group, the moderator's actual or perceived attributes, and normative public discourses on a set of issues (Smithson, 2000). It was felt that this could be countered by preparing participants in advance of the focus group discussion via sharing the research team's enthusiasm to value everybody's unique contributions and ensuring that all participants were familiar with the group guidelines. An active approach to moderating further safeguarded groupthink by inviting different group members to speak or 'playing the devil's advocate' to stimulate discussion (MacDougall & Baum, 1997).

To meet the aims of the research, consensus development methods such as the Delphi methodology (Dalkey & Helmer, 1963) were considered but discounted. Delphi studies have been used in clinical psychology research to systematically explore and approach a consensus view on topics with limited knowledge, clarity or where controversies exist (Iqbal & Pipton-Young, 2009). The method involves structured group communication processes, where knowledge about a concept is requested from experts in the field through questionnaires. A defining element of the Delphi technique involves the aggregation of findings from a questionnaire, which is then supplied with a further questionnaire to experts, to request a re-considered opinion based on the information presented in the previous stage (Niederberger & Spranger, 2020). A critical element of a successful Delphi survey involves the selection of respondents and how the required expertise is operationalised for the panel (Hasson & Keeney, 2011; Nasa et al., 2021). Due to the early stage of the evidence base for compassion training with parents, it would be difficult to operationalise who might be classed as an expert for the purpose of the research. Furthermore, Delphi studies do not involve direct communication between participants, which is a direct contrast to focus group

methodology. It was felt that the communication between participants to discuss their views about the CMT-PAC was an invaluable strength of the present research, and this may also aid in the establishment of collaborative relationships with the researchers.

Further consensus building methodologies with greater participant interaction were considered and discounted. The nominal group technique (Delbecq, 1975; Cantrill et al., 2011) is a highly controlled and structured method of obtaining reliable qualitative information from expert groups within a focus group setting and can support problem identification, solution generation, and action prioritisation. The process involves five set phases; introductions and an explanation of the process, silent idea generation, a round robin approach for each participant to share their ideas until all have been voiced, a group discussion to provide idea clarification, and lastly, a voting and ranking phase for ideas to take forward in order of prioritisation (Harvey & Holmes, 2012). A key strength associated with the technique involves the ability to maintain balanced involvement with all attendees through use of the round robin technique, which may prevent the risk of dominant voices within group meetings, as can occur in less structured meetings. However, because of the highly structured format, there remains a lack of between-participant discussion and a lack of flexibility about addressing more than one idea at a time. It was felt that the mechanical nature of the setting may appear inaccessible or overly restrictive to PAC participants with differing communication preferences and a lack of experience in research-related discussions, which might have led to disengagement by some, so the technique was discounted to promote further flexibility. This same disadvantage also led to a further consensus building methodology, termed the RAND/UCLA Appropriateness Method (RAM; Fitch et al., 2001), to be discounted. The RAM is understood to be a two-round “modified Delphi” process that differs from usual Delphi studies due to the involvement of direct interactions between participants in the second round. The RAM differs from nominal group technique, as the former begins with a structured list of clinical indicators relating to a health subject matter, and the opportunity for discussion amongst expert participants is specifically linked with measurable ratings of appropriateness and necessity.

Online methods were used as this was hoped to promote greater flexibility and less cost for participants to attend, rather than participants needing to travel to a physical location (Stewart & Shamdasani, 2017). This felt important as it is known that target participants are likely to experience several competing demands such as

childcare arrangements and their employment. Additionally, this broadened the geographical area for eligible participants to be able to access the study. Furthermore, the functionality of Microsoft Teams enables additional methods to support turn-taking in conversations such as the 'hands up' feature and chat function, as well as verbal contributions, which could be used as a reasonable adjustment for people with communication and interaction differences (Hersh et al., 2024). Online focus groups have been applied in a wide range of settings, including health care and social science research (Gaiser, 2008; Stewart & Shamdasani, 2017) and can perform as effectively as face-to-face groups in terms of information elicitation from attendees (Reid & Reid, 2005; Underhill & Olmsted, 2003). However, it is recognised that those without access to the relevant technology including the estimated 2.2% of the UK population without internet access (Kemp, 2024) would be excluded from the research, causing the potential for sample bias. This limitation was felt to be justified when comparing this to the increased number of people who could access the research due to reasons already discussed. Video conferencing methods can make it more difficult to monitor non-verbal cues during focus groups, as can be crucial for methods such as conversational analysis (Lobe et al., 2022). The field supervisor's attendance during FG1 and FG2 attempted to mitigate this as much as possible through noting non-verbal observations during focus group facilitation, but it is acknowledged that this does not fully nullify this limitation.

Finally, to date there are research gaps related to formal techniques to compare the content from different interviewing formats, meaning that conclusions regarding the quality and usefulness of online versus face-to-face focus groups cannot yet be firmly understood (Lobe et al., 2022; Lobe & Morgan, 2021). Alternative methods for assessing quality of focus group outcomes, such as expert judgements and participant ratings, require further exploration, as current standardised tools to support this are limited to single scores for overall quality (Lobe et al., 2022). Therefore, standardised tools were not used to indicate facilitation quality during the present research, but reflective discussions between the lead researcher and field supervisor were facilitated immediately after FG1 and FG2, and further reflections were discussed within research supervision with other research team members.



## 2.6 Development of Interview Schedules<sup>58</sup>

The semi-structured interview schedules for each PAC focus group focussed on obtaining answers to the research aims by seeking parents' views around the corresponding version of the CMT workbook. Items in the interview schedules were driven by *a priori* knowledge within the research team and further reading (Eldridge et al., 2016; Sekhon et al., 2017) around these key concepts. The second parent focus group interview schedule aimed to support participants to provide their views on the updated intervention, with the assumption that they had been involved in the previous focus group. However, attendees were a mix of new and returning participants due to participant drop-out, and so questions were framed more broadly in the meeting to enable meaningful contribution from all participants. Discussions where participants reflected on these differing positions and how these influenced their views about the resource were brought up by participants and welcomed by the moderators. The CP focus group interview schedule was developed during the change to study design and aimed to broadly provide answers to the same concepts from clinician perspectives. Questions were adapted from a previous study supervised by one of the research team members (Marlow et al., 2023) which held similar research aims.

## 2.7 Research Procedure

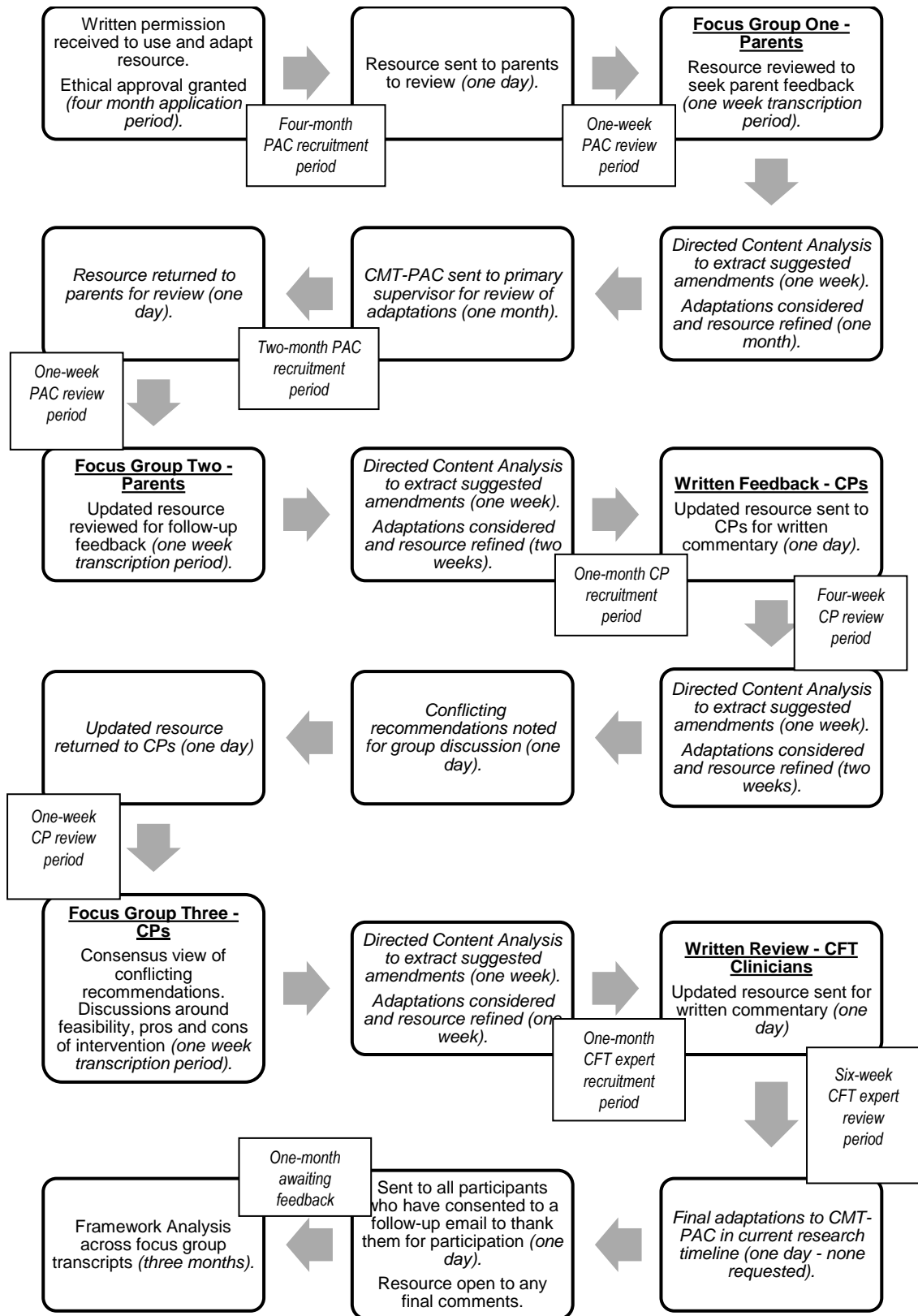
Figure 1 provides a visual depiction of how the research was conducted.

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<sup>58</sup> See Appendices L, M and N for Interview Schedules for each focus group.

**Figure 1**

*Process Chart for Research Procedure*



## **2.8 Justification for Analytic Methods Used and Other Methods Considered**

The research aimed to identify and describe concepts that arose within rounds of stakeholder feedback, such as stakeholder amendment requests, and their views about the anticipated factors influencing successful implementation of the CFT resource during future feasibility testing. Qualitative analytic methods remain appropriate for focus group datasets with multiple participants (Kitzinger, 1995). The purposes of differing qualitative methods may be understood by their underlying epistemological positions and aims of each approach (Spencer et al., 2014). They vary from developing new theories (Glaser et al., 1968), to exploring how participants construct meaning around their context or experiences through stories (Labov, 1982) or language (Potter, 2012), to identifying, describing, and interpreting phenomena in written or spoken datasets (Braun & Clarke, 2006; Elo & Kyngäs, 2008). Approaches which did not meet the aims of the research, such as Interpretative Phenomenological Analysis (Smith et al., 2009), Discourse Analysis (Potter, 2012), Grounded Theory (Glaser et al., 1968) and Narrative Analysis (Labov, 1982) were ruled out immediately as these did not focus on the identification and description of key concepts within the dataset.

From the qualitative approaches that could meet the aims and purpose of the current study, Thematic Analysis (Braun & Clarke, 2006) and Qualitative Content Analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005) remained for further consideration. Both approaches share similar aims; to examine narrative materials through coding text into smaller units of meaning for further descriptive analysis (Vaismoradi et al., 2013). Both approaches have been flexibly used inductively and deductively in published literature, and thematic analysis has been described as the foundational approach for new qualitative researchers (Braun & Clarke, 2006). The potential analytical findings from the two approaches differ in scope, where content analysis may function to quantify the frequency of codes or themes within a dataset, whereas the results of thematic analysis are purely qualitative through referring to example quotations from the raw data (Vaismoradi et al., 2013).

### ***2.8.1 Justification for Directed Content Analysis***

The present study design involved two processes; the iterative analysis of stakeholder suggested amendments at each round of feedback to support rounds of

intervention refinement, followed by a broader analysis across focus groups to identify and describe key views regarding the anticipated factors influencing successful implementation of the CFT resource during future feasibility testing. Directed Content Analysis (DCA) was chosen to meet the aims of the former process, as it can be used deductively to compare the frequency of items in categories at different periods (Elo & Kyngäs, 2008; Vaismoradi et al., 2013). This was particularly appealing as it enabled the categorisation of amendments and comparisons between the types of suggested amendments received during each round of feedback. DCA has been used as a rapid coding process (Neal et al., 2015) for similar studies to provide a time-efficient methodology for extraction and enactment of stakeholder feedback (Ametaj et al., 2021; Radovic et al., 2017), which was felt to be valuable when considering the constraints and available resources throughout the research timeline. A critique of DCA involves scepticism around the appropriateness of quantifying qualitative data, as this may risk misinterpretations around the generalisability of the research findings. In the present study, frequencies were only reported in terms of the number of adaptations completed during each round of intervention refinement, to prevent such misinterpretations and to supplement transparency in reporting the adaptation process, as is best practice for intervention development research publications (Skivington et al., 2021b).

### **2.8.2 Justification for Framework Analysis**

After changes to the study design, it was felt that further analysis was beneficial to identify and describe the range of views across stakeholder groups about the anticipated factors influencing successful implementation of the CFT resource during future feasibility testing. This attempted to bridge a gap often recognised in intervention development studies, where the understanding around how and why adaptations have occurred often remains unclear (Holtrop et al., 2022). To meet this research aim, Thematic Analysis (Braun & Clarke, 2006, 2012, 2013) was considered. Thematic Analysis can be utilised across a range of theoretical and epistemological positions to provide rich understandings around complex phenomena (J. Smith & Firth, 2011). However, the approach has previously been criticised for being a “*poorly demarcated, rarely acknowledged, yet widely used qualitative analytic method within psychology*” (Braun & Clarke, 2006, p. 77), which resulted in the guidelines developed by Braun and Clarke in 2006. The authors have since acknowledged the misapplication of these

guidelines and have since termed their approach as “*reflexive thematic analysis*” (Braun & Clarke, 2021a) to highlight the theoretical stance of the analyst and the continual need for awareness regarding the underlying assumptions influencing data analysis and interpretation.

Further criticisms relate to the perceived linear usage of thematic analysis and a lack of clarity around how themes are developed, which reduces the perceived rigour of the results as it is unclear how data are interpreted by analysts (Smith & Firth, 2011). Framework Analysis (FA; Gale et al., 2013; Ritchie & Spencer, 1994; Smith & Firth, 2011; Spencer et al., 2014) is an approach positioned within Thematic Analysis which may counter such criticisms by providing a more structured format for data management and interpretation. Centrally, the analytic process is conceptualised as a series of interconnected stages which enable the analyst to move back and forth across large datasets to develop a conceptual framework (Ritchie, 2014). This approach uses a framework to illustrate the linkage between raw data and all stages of the analytic process, providing better transparency and replicability (Smith & Firth, 2011). This appealed to the lead researcher as it also supplemented discussion around ongoing data analysis within research supervision.

## **2.9 Directed Content Analysis Process**

The DCA process followed three phases as described by Elo & Kyngäs (2008). These are described below.

**Preparation phase.** In deductive DCA, the first step involves selecting the appropriate unit of analysis, whether that be the presence of certain words, sentences, number of participants in discussion, or the time used for discussion (Elo & Kyngäs, 2008). The current study aimed to systematically adapt the CMT resource through feedback from relevant stakeholders, and therefore a unit of meaning was defined as one or more sentences that clearly identifies a negative reaction towards an aspect of the proposed intervention, or when a suggestion for amendment was made. The unit of analysis was determined to be each whole focus group interview or set of written feedback, as these were “*large enough to be considered as a whole and small enough to be kept in mind as a context for meaning unit during the analysis process*” (Elo & Kyngäs, 2008, p. 109). During this phase, a decision must be made around whether to code manifest content only, or the latent content (e.g. laughter, pauses) as well. In the

current research, only manifest content was analysed as it was felt that latent content would involve more interpretation, which would move beyond the aims of the research. Finally, data were read several times so that the analyst could immerse themselves in the data.

**Organising phase.** The next step involves the development of a categorisation matrix, sometimes referred to as a codebook<sup>59</sup>, to systematically code the data. Either a structured or unconstrained matrix of analysis may be used, depending on the purpose of the study. In the present study, the FRAME (Stirman et al., 2013, 2019) was used to guide the structured categories for the coding matrix. Specifically, aspects of modification within '*nature of content modifications*' and '*contextual modifications are made to which of the following*' within the FRAME were utilised to code requested amendments and negative comments about aspects of the workbook. FRAME was selected for use as it is an evidence-based and widely used intervention modification reporting framework, and the categories were felt to meet the first study aim (to extract suggested amendment requests from stakeholder feedback). These categories supplemented the desired outcome of the DCA, as adaptation summaries could be created, which would enable a clear audit trail for the adaptation process and clearer reporting, as is best practice (Stirman et al., 2019).

Once the categorisation matrix is formed, the analyst reviews all data for content which is relevant to the study aims and corresponds with the identified categories within the matrix.<sup>60</sup> In the present study, NVIVO14 was used to code the data according to structured categories. During this phase, inter-rater reliability checks were performed by having an independent doctoral researcher separately code a transcript excerpt and allocated parent comments to different codes.<sup>61</sup> Finally, the organising phase can also involve further data analyses such as hypothesis-testing, correspondence comparison to earlier studies, etc. depending on the study aims. In the present study, the aim was to produce summaries of adaptation requests for the research team to consider prior to refinement of the CMT intervention. All coded data were exported to a Microsoft Excel spreadsheet<sup>62</sup> for further consideration and the reason for adaptation using categories from the FRAME were interpreted through

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<sup>59</sup> See Appendix O for the codebook used during the Directed Content Analysis.

<sup>60</sup> See Appendix P for example coding from the Directed Content Analysis.

<sup>61</sup> See Appendix Q for inter-rater reliability checks using Cohen's Kappa Coefficient.

<sup>62</sup> See Appendix R for excerpt from Microsoft Excel database for tracking adaptation suggestions.

reviewing the raw data within the transcript. Further amendments completed by the research team which did not follow an amendment request by stakeholders were added to the spreadsheet to track adaptations. The frequencies for nature and reasons for adaptations per phase were calculated using the PIVOT table function in Microsoft Excel to inform the taxonomic analysis.

**Reporting results phase.** In this stage, a detailed description of the analytic process, quality considerations, and the outcomes of the DCA are reported. Findings should be systematically documented with clear links to the raw data and the categorisation matrix (Assarroudi et al., 2018). The present study used the FRAME (Stirman et al., 2019) to report study findings in the journal paper in table format, with example quotes provided in the extended results.

## **2.10 Adaptation Protocol**

The adaptation of an evidence-based intervention can be complex and multi-faceted, where one adaptation may result in a chain reaction of potential intended and unintended outcomes, which may influence the acceptability, feasibility and fidelity of the intervention (Kirk et al., 2020). It is therefore crucial that the potential consequences of adaptations are carefully considered, to reduce the possibility of unintended outcomes that may reduce the effectiveness of CMT-PAC. The possible mediating or moderating factors listed within the MADI were used as criteria for decision-making during the adaptation process. The following questions were considered:

- 1. Would the adaptation be consistent with the core functions of the intervention or future implementation strategy?*
- 2. Is the adaptation being made for a reason or goal to address fit?*
- 3. What could be the impact on outcomes, considering available data, theory, stakeholder opinions and best practice?*
- 4. Is the adaptation being made due to an anticipated obstacle? (Kirk et al., 2020, p. 8)*

During each refinement phase, the lead researcher extracted all adaptation requests and negative feedback about the CMT resource into a Microsoft Excel table, as stated in section 2.9. Any negative comments were reviewed by the lead researcher to check whether these related to a subsequent adaptation request by

reading back through the raw transcript. Where no specific adaptation request could be linked, the lead researcher pragmatically inferred what adaptation could be reasonably assumed to rectify the negative feedback through consideration of the DCA themes identified throughout the focus group and sought research supervision about this where necessary. Next, Microsoft Word tables<sup>63</sup> were created for each of intervention refinement, to document the thought process behind the appropriateness and potential outcomes of each adaptation request. Where the lead researcher experienced doubt around the appropriateness of an adaptation, such as when there was anticipated disagreement between key stakeholders within and between focus groups, this was brought to research supervision for a consensus decision on whether to proceed. During these circumstances, the lead researcher would present the adaptation request to the research team, describe the anticipated factors for and against implementing the recommendation, and then facilitated supervisory discussion to seek a consensus opinion between at least three of four research team members regarding how to proceed (i.e., whether to incorporate both, one, or neither conflicting amendment request). The research team involved members with formal CFT training and experience working with autistic children and their families, and so were well-placed to offer evidence-informed opinions regarding the appropriateness of adaptations requests to be facilitated.

Once the scope and description of all proposed adaptations was understood and agreed, the lead researcher independently implemented adaptations systematically through the CMT resource using the Microsoft Word track changes function. The lead researcher filled out the Microsoft Word adaptation request tables to document where and how each adaptation had been implemented, for the purpose of keeping an audit trail. Furthermore, both a 'clean copy' and a 'track changes' version of the workbook from each refinement phase was kept within the research electronic file, for retrospective reviewing by the research team if needed. After FG1, the lead researcher requested that the refined workbook was reviewed by the primary research supervisor due to the significance of changes made to the resource, to seek opinion on whether this remained theoretically coherent and appropriate to return to FG2 participants for further feedback.

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<sup>63</sup> See Appendix S for excerpt from Microsoft Word tables for tracking decision-making for adaptations.



## **2.11 Taxonomic Analysis**

Although adaptation classification frameworks such as FRAME (Stirman et al., 2019) are widely used to categorise and report the descriptive components of intervention adaptations, their use alone can present methodological challenges for future analysis and interpretation during later piloting phases. Individual components with several descriptive elements (e.g. nature of adaptation, goal of adaptation) may become difficult to interpret, such as when attempting to unpack how adaptations improve fit for a recipient population, or within future feasibility and efficacy studies when investigating the outcomes from intervention adaptations. Holtrop et al. (2022) detailed existing methods that may be used to group multiple classifications of individual elements to summarise how these cluster together as adaptation types. These could enhance future analyses by mitigating the challenges previously identified.

Following methods by Holtrop et al. (2022), a table was created that included all adaptation component combinations for adaptation category and rationale. FRAME categories that were not coded were removed, to ensure the table was a reasonable size for interpretation. Within the adaptation tracker Microsoft Excel spreadsheet, a PIVOT table was created to count the frequencies for every combination of the above adaptation components, during each round of CMT-PAC refinement. Table 3 showed all combinations present in the data, with the count of how often each combination occurred per phase and the total number of adaptations completed per phase.

## **2.12 Framework Analysis Process**

The FA was conducted on focus group transcripts only and did not include written feedback summaries from phases three and five of the research procedure, as the approach cannot accommodate highly heterogeneous data (Gale et al., 2013) such as individual versus group feedback involving different types of prompts within the feedback requests. Written commentaries remained largely focused on adaptation requests, rather than providing data that may meet the second research aim. The analytic method involved six steps, described below.

### **2.12.1 Data Management**

Data management involved decisions around the themes and concepts that the data would be labelled, sorted and compared prior to data analysis (Ritchie & Spencer, 1994; Spencer et al., 2014). This followed five steps, described below.

**Data familiarisation.** Like most qualitative analytical approaches, it is imperative that the data analyst gains an overview of the data coverage by becoming thoroughly familiar with the dataset. This crucially provides the analyst with initial knowledge to build the foundations of the initial framework in step two. The amount of time and effort spent during familiarisation might depend on various factors including the analyst's involvement in the previous stages of research and the volume of data collected. In the current study, the lead researcher was familiar with the data through leading earlier stages of data collection and conducting the DCA. Nevertheless, all focus group transcripts were read multiple times and the researcher noted initial themes or concepts that appeared predominant. Identified topics of interest must be relevant to the research questions being answered and should be prevalent across multiple datasets (Spencer et al., 2014).

**Construction of the initial framework.** Using *a priori* issues defined within the research aims, alongside recurring themes or patterns in the data that emerged through the familiarisation process, an initial framework is developed to sort and organise the data (Spencer et al., 2014). The framework is usually descriptive at this stage but is respondent to more analytical themes when applied to transcripts and can be refined where data does not seem to fit. Throughout this process, the analyst must carefully consider whether the coding process is focused on gathering data to meet the research questions. To keep the research questions at the forefront of the lead researcher's thinking, a post it note with the questions were stuck to the researcher's laptop screen during analysis. In this phase, analysts will need to make assumptions about the significance and meaning of data (Ritchie & Spencer, 1994). The framework used within the present research was created from topics listed within the third focus group interview schedule, as these appropriately linked to the second research question. Initial themes related to the anticipated feasibility and acceptability of CMT for PAC and services, and the potential barriers and facilitators when PAC will access CMT.

**Indexing and sorting.**<sup>64</sup> At this stage, data were systematically applied to the initial framework using a hybrid inductive-deductive approach, where data were sorted into categories in the framework if applicable, and new themes were developed to sort data that appeared relevant but did not fit existing themes. It is not uncommon to find multiple themes within close proximity during areas of complex discussion, and so occasionally data were sorted into multiple themes (Spencer et al., 2014). In such cases, the lead researcher noted this to support later analysis for when linkage between themes is considered. Data is then sorted so that all similar raw data can be viewed for each theme. In the current research, use of NVIVO14 enabled indexing to be quickly facilitated, and the software provided functionality to view sorted data grouped by theme to enhance the review of data extracts.

**Reviewing data extracts.** Once all data were indexed, the raw data within each theme were reviewed to assess whether the data fit coherently. Often this results in the initial framework being refined, which should be noted by the analyst as this is likely significant within later data interpretation (Spencer et al., 2014). If this is the case, the refined framework should be systematically applied to all transcripts through further indexing. Therefore, the analyst may find themselves moving between earlier stages of data management until they are satisfied that data is coherently organised. In the current study, specific subthemes emerged through the indexing process. Therefore, the framework was refined into six key themes: 'competing demands and limited time', 'perceptions of compassion', 'facilitators for intervention engagement', 'making the resource neurodivergent-friendly', 'current service availability' and 'potential impact from intervention'. Further initial subthemes are detailed within Table 4. Indexing was repeated and further review of the new datasets showed greater coherence.

**Data summary and display.**<sup>65</sup> At this stage, framework matrices were developed for each theme, where each column represented a sub-theme, and each row represented a unit of analysis (focus group). This enabled the relevant data per subtheme and participant to be charted into the framework matrices. Unlike other qualitative analyses where data are extracted verbatim at this stage, during FA all data undergoes a process of extraction and synthesis, where the analyst writes a succinct summary of the data extract. It is important that the participant's voice is not lost at this

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<sup>64</sup> See Appendix T for example indexing during the Framework Analysis.

<sup>65</sup> See Appendix U for an excerpt from the Framework Analysis data summary and display in NVIVO14.

stage as it should not be overly interpreted, but data must be synthesised to prevent the matrices from becoming overloaded with unprocessed data, as this diminishes the ability to read across matrices during later interpretation (Spencer et al., 2014). Although this stage is usually the most time and resource intensive, it was this stage that made FA particularly appealing for the present research as the framework matrix function within NVIVO14 remained directly linked to the raw data to support transparency and accessibility for cross-checking within research supervision.

There is risk that data become quantified at this stage through stating how many participants contributed to key dimensions within each focus group. This may infer generalisability of the dimensions identified, which is not the purpose of the FA and would be inappropriate. To mitigate this, the focus group participants were analysed as one voice, although different ranges of views were documented within the matrix where relevant. For example, differing views about the use of colour in chapter two were documented in the second focus group cell under the 'visuals and interest' subtheme under the 'facilitators' theme, with participants' differing rationales.

### ***2.12.2 Data Interpretation***

Once data management is completed, the formal process of interpretation can occur. How data are interpreted is reliant on the study aims, but this may include descriptive and explanatory processes. Descriptive analysis involves reviewing each column of the framework matrices and identifying key dimensions or elements within the subtheme. These dimensions are then reviewed to abstract key categories identified within the data. Throughout this process, links with the raw data should be upheld so that the analyst can easily consult raw data to support identification of elements and categories. This process may happen iteratively and multiple times, until the researcher is satisfied with the theme structure and key concepts defined.

In the current study, the framework matrices were exported into a Microsoft Excel spreadsheet and two further columns were added to the right of each subtheme. The key dimensions and elements were recorded in the first column to the right for each cell of the subtheme column. Next, categories identified were recorded into the second column to the right, and colour-coded with the corresponding elements and

dimensions column.<sup>66</sup> To support consistency during the interpretation phase, a separate Excel sheet listed all categories identified within columns, with all corresponding elements documented underneath to uphold transparency and support the researcher to review whether categories upheld coherence and consistency.<sup>67</sup>

Some analysts stop at the defining concepts stage; however, others might involve further steps such as mapping the 'linkages' between sets of phenomena or establishing typologies (Spencer et al., 2014). Further processes can be utilised to infer explanatory concepts from the data to build explanations (Spencer et al., 2014), however this was not facilitated in the current study as this was not the aim of the research. The research aims involved identifying the key views amongst stakeholder groups and therefore data interpretation ended after the descriptive analysis, as stakeholder feedback did not require further explanation.

## **2.13 Research Quality Considerations**

Qualitative studies can be assessed for quality through using appropriate frameworks, such as the Critical Appraisal Skills Programme (CASP; 2019), which provides ten broad areas of potential issues to consider that indicate study rigour. The CASP was chosen to support the appraisal of the present research design during early planning stages, although it is acknowledged that the study differed from a usual qualitative study procedure. Nevertheless, it was further consulted during later stages of altering the research procedure.

### ***2.13.1 Planned Within-Group Sample Sizes***

Guidelines for focus group size are varied, although typically a minimum of four to a maximum of twelve participants per group is recommended (Kitzinger, 1995; Krueger & Casey, 2015; Stewart & Shamdasani, 2015). However, it is recognised that such numbers have emerged as ideals from market research literature, are not substantially empirically supported, and some researchers have advocated for smaller

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<sup>66</sup> See Appendix V for an example of the descriptive analysis process during the Framework Analysis.

<sup>67</sup> See Appendix W for an example of how categorisations and themes were grouped into key concepts within Microsoft Excel.

group sizes in social science research (Barbour & Kitzinger, 1999). Development of proposed sample sizes in focus group research should involve the consideration of several factors relating to the characteristics of participants and the subject matter to discuss, as these factors may support the formation of an optimum size and composition of a group (Bloor, 2001).

Smaller focus groups with as low as three participants are favoured by some researchers, depending on the context of the research aim (Barbour & Kitzinger, 1999). Small groups can be advantageous when used with participants with expertise or additional needs to ensure that each has enough time to express their views (Barrett & Kirk, 2000; Gates & Waight, 2007; Morgan, 1995). The recruitment of smaller sized groups may also naturally occur due to logistical constraints should the participant pool be initially small, or if several participants fail to attend. Possible limitations associated with small group sizes involve the inevitable smaller quantity and diversity of experiences to draw upon which may limit discussion (Plummer-D'Amato, 2008), and the risk of cancellation due to non-attendance of one or more participants. On the other hand, although larger groups may provide a higher number of experiences to draw on, it is argued that they may become difficult to moderate, may limit opportunities for all participants to contribute, and may cause difficulties with transcription and analysis of audio-recorded data due to the number of voices in the group (Bloor, 2001).

Taking the above into account, the present research aimed to recruit five PAC participants, as it was felt that this would support balance between promoting diversity of experiences within the focus group discussion, whilst ensuring that all participants had sufficient time to express their views about the intervention during a ninety-minute session. The recruitment strategy for CPs was broadened to include four to eight participants, to support the balance of maximising the time available for all participants to share their expertise during the focus group, with the ability to recruit more people to minimise the impact of participant drop-out, following experiential learning during recruitment difficulties during earlier phases of the project.

### **2.13.2 Researcher Reflexivity<sup>68</sup>**

Reflexivity is defined as “a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes” (Olmos-Vega et al., 2023, p. 242). Unlike quantitative research methods which aim to uncover objective truths, qualitative research is dependent on subjectivity, as how a researcher chooses to shape and engage with their enquiry will inevitably influence how data are collected, analysed, and presented (Elliott, 2005). Reflexivity in qualitative research may be oriented towards four domains; personal, interpersonal, methodological, and contextual issues within the research (Olmos-Vega et al., 2023). Several factors supported an ongoing process of reflexivity throughout the research process. The lead researcher kept a reflexive log and brought key reflections to discuss during monthly supervision with the research team.

### **2.13.3 Inter-Rater Reliability during Directed Content Analysis**

Cohen's (1960, 1968) kappa coefficient was chosen to support inter-rater reliability assessment as it is a chance-corrected statistic that is regularly used to evaluate inter-rater agreement for coding of dichotomous items, and items with multiple response categories (De Vries et al., 2008). This made the statistic applicable for both aspects of inter-rater agreement that required assessment; the presence or absence of amendment suggestions within raw data, and the accuracy that raw data were each coded using several descriptive elements relating to the FRAME (Stirman et al., 2019). The approach is more useful than calculating percentage agreement rates alone, as the statistic compares agreement rates whilst sensitive to the rate of agreement based on chance alone, based on the overall coding rates for each coder. To assess the inter-rater agreement using multiple coding elements for the same data, a pooled kappa estimator was used as this is evidenced to have greater precision when estimating agreement for coding using multiple category groups, in comparison to simply averaging all item-level kappa statistics (De Vries et al., 2008).

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<sup>68</sup> For details, see section 5.0 for a reflective account regarding the research process.

#### **2.13.4 Considerations around Data Saturation**

Data saturation is broadly defined as information redundancy (Lincoln & Guba, 1985), where no new information, codes or themes are extracted from data (Braun & Clarke, 2021b). The concept was originally associated with the grounded theory method to indicate theoretical saturation for production of a theoretical framework (Glaser et al., 1968; Morse, 2015). However, it has since become broadly applied as an indicator of rigour in qualitative research and is often cited as a guiding principle to assess the adequacy of data collected within qualitative research (Hennink et al., 2019). The broad use of data saturation as a 'gold standard' for qualitative enquiry is critiqued, as it has been used imprecisely as the main rationale for sample sizes in some qualitative research, and it is not appropriate for all qualitative methodologies (Braun & Clarke, 2021b; Nelson, 2017). Low (2019, p. 131) argues that data saturation is a "*logical fallacy*", where new themes will likely always arise through ongoing data collection with more participants. The present study did not follow a typical qualitative design, as the iterative process of participant feedback rounds and intervention refinement meant that each stage of feedback had commented on a different version of the intervention, and so information redundancy was unobtainable. Therefore, data saturation is not used as an indicator of rigour for the present study.



### 3.0 Extended Analysis

#### 3.1 Summary of Adaptation Process

A detailed account of the adaptation process during phases one to four of the research is documented below.

##### **3.1.1 Phase One: First Parent Focus Group**

The group provided a mixture of positive and negative comments about the psychoeducation content about the 'tricky brain' and 'preparing for practice' topic areas, but most feedback was negative relating to the overall intervention, as documented in the journal paper. All attendees did not find the intervention acceptable or feasible for PAC. Following de-duplication of coded suggestions from participants, a total 57 suggestions for adaptations were reviewed. Due to the significant amount of negative feedback spanning the entire workbook content and structure, it was decided that re-writing the workbook material would be more time efficient than attempting to systematically adapt the existing workbook to such a significant extent. Due to the significance of the amendment procedures, the primary research supervisor reviewed the draft changes prior to this being sent back to parents for further review.

**Content Modifications.** The workbook was re-developed as a six-chapter intervention with assigned audio tracks for daily practice each week. Efforts focused on providing clearer intervention rationale through adding an introduction to the workbook, timetable for practice, and learning objectives, and the addition of summaries to reinforce section objectives at the beginning and end of each chapter. The amount of text was reduced by incorporating more diagrams, text boxes and speech bubbles. Colour coded text boxes were incorporated to signal tips, examples, and exercises to try. Examples deemed irrelevant by parent stakeholders were removed and replaced with examples linked to contextual themes discussed within the focus group.

**Contextual Modifications.** Participants shared strong preferences for the intervention including guided support through a check-in with another person using a choice of communication methods. Parents felt that it would be feasible to engage with the intervention for approximately 10-15 minutes daily, and so this was kept in mind throughout the process of content modifications. Parents shared concerns around the

barriers to engagement whilst their child awaited an autism assessment, and so the intervention criteria was broadened to include those with children on an assessment waitlist.

**Disregarded.** One parent suggested that the researcher must have lived experience as a parent of an autistic child to be able to adapt the intervention, which was not feasible. This parent also stated that the intervention did not need to discuss detail around brain functioning and should instead focus on the experiential exercises. Content around the ‘tricky brain’ was not removed as this was felt to be a core component of CFT, but efforts were made to reduce language and amount of text to read, and to introduce the concept with a clearer rationale for the psychoeducation component of CFT. A request to change the word “imagery” to “pictures in your mind” to improve fit with recipients was not implemented, as this did not accurately define the concept of imagery, but a definition of imagery was added when this was introduced in chapter three.

**Identified as future considerations when CMT-PAC is tested.** Suggestions to reproduce the content in different languages and video formats were not implemented at this stage because the intervention content was not yet finalised. It was felt that efforts to reproduce content that may require further amendments would incur unnecessary costs, but these recommendations would be documented for future research.

### ***3.1.2 Phase Two: Second Parent Focus Group***

The group provided positive comments around the updated tone of the intervention and how their experiences were captured. Constructive feedback was provided to increase the clarity of psychoeducation through use of examples, to improve the formatting of the workbook, and to correct a small number of typing errors. All found the updated intervention feasible and largely acceptable. Following de-duplication of coded suggestions, a total 33 suggestions for further adaptations were received.

**Content Modifications.** Labels for the three emotion systems were added to diagrams to emphasise how often each system might activate to support accessibility. An example was added to the ‘power of attention’ to support parents’ understanding around how being able to notice which mini-self has ‘taken the stage’ can enable

parents to consciously choose to move to their 'compassionate self'. The word 'diaphragm' was changed to 'stomach' in experiential exercises to meet recipient literacy level. Several typos were corrected, and formatting recommendations, such as increasing the roundness of speech bubbles and transforming spiky text boxes into cloud shapes, were completed to increase recipients' satisfaction regarding the workbook visuals. A diagram defining common autistic traits was colour-coded by diagnostic criterion with a key provided to enhance accessibility. A troubleshooting question and answer for 'what if I get distracted by an interruption partway through?' was added to chapter three, in reference to the likelihood of recipients managing competing demands. References to key studies were added to evidence key findings around the benefits of compassion in chapter four, to enhance recipients' perceptions about the effectiveness of CMT, and provide signposting to optional further reading. Further tweaks in wording occurred in various places throughout the booklet with the aim to model compassion within the text, such as at the beginning of the final chapter, where a compassionate acknowledgement was added to highlight that it is okay if getting towards the end of the workbook has taken longer than planned.

**Disregarded.** A suggestion to broaden the scope of the target population group to parents and carers was not implemented as the content was deemed to lack specificity for carers who do not hold a parental or legal guardian relationship with their child. A suggestion to incorporate a gratitude journal component into the compassionate letter writing exercise was felt to be theoretically incoherent with the core function of this exercise. A request to change the colour of the soothe circle to purple in the three emotion systems was not implemented, as no clear rationale was provided, and this contradicted the usual theoretical model.

**Identified as a future consideration when CMT-PAC is tested.** Suggestions to reproduce the content in different languages and alternative formats including video and audiobook were not implemented at this phase, due to the same rationale as phase one.

### ***3.1.3 Phase Three: Written Feedback from CPs***

Four CPs provided a total of 152 comments, including 73 suggestions for further adaptations. Positive comments related particularly to elements where language in the workbook appeared less formal, and occasions where content specifically

modelled compassion whilst relating to the common stressors linked to parenting an autistic child. CPs shared suggestions largely relating to increasing accessibility and fit with recipients. Nine suggestions conflicted with other CP feedback or feedback received from previous phases, so were not yet actioned but noted and taken to the phase four focus group discussion.

**Content Modifications.** Most modifications involved minor amendments to the language used to meet a wider range of recipient literacy and education levels. Some psychoeducation elements were broken into smaller sections to support recipient information processing (e.g., the ‘unhelpful thinking loops’ section in chapter one was broken down into two sections: ‘what happens in animal’s brains’ and ‘what happens in human brains’). A brief note about the rationale for terminology used to describe autism was added within the workbook introduction to acknowledge different preferences. Two character stories, including a neurodivergent mother, were added to the workbook introduction to link these to later examples and troubleshooting advice throughout the workbook. Reflection boxes were added after each experiential exercise for parents to write about their experiences, in hope this could strengthen their practice. Troubleshooting advice and visual information was provided prior to the first practices (compassionate posture, facial expression, and voice tone) for recipients who may experience difficulties with interoception. A brief ending letter was added after the final workbook chapter, to compassionately acknowledge the ending of the workbook.

**Disregarded.** One CP suggested that further troubleshooting advice was provided prior to daily practices for chapters one and two. Aspects were not added as it was felt this would repeat elements already existing in week one and week three. Suggestion to change the colour-coding for text boxes so these were not the same colours used in the three-emotion regulation systems model was not implemented as there were not enough vastly different colours to choose from within Microsoft Word software. Alternative subheading suggestions (e.g., “life hacks” instead of “time for practice”) were not implemented as these were felt too abstract and possibly misrepresented the function and rationale for experiential exercises.

### ***3.1.4 Phase Four: Focus Group Discussion with CPs***

A total of 24 further suggestions were provided for review.

**Content Modifications.** CPs felt that starting the resource by explicitly relating compassion to parenthood would support recipient motivation and engagement with the resource, so chapters one and two were re-ordered. The definition of compassion was added to the end of the first chapter, following information around the challenges of parenthood. Signposting to chapter three (preparation for practice) was added throughout each experiential exercise; to support troubleshooting procedures should recipients have difficulty completing the exercises. The first compassionate imagery exercise in chapter three was split into a shortened (developing a compassionate image) and extended (developing and using a compassionate image) version to improve feasibility and recipients' motivation to engage with the exercises. An optional compassionate object exercise was added in the final chapter to function as a transitional object. The experiential exercise in chapter four included a new example prompt of 'other parents of autistic children', alongside existing prompts when recipients are asked to think of someone to direct compassion towards, such as a family member or friend. The references to compassion studies requested by parents were re-formatted as footnotes to improve accessibility.

**Disregarded.** CPs suggested that an early exercise to experience compassion could support recipients' motivation to engage. Examples such as the addition of compassionately imagining a parent going about their day were discussed, but others felt that existing exercises could be used. It was decided that existing exercises could meet this goal. CPs suggested that the 'preparing for practice' section in chapter three could be moved to pre-chapter one, or alternatively as an appendix at the end of the workbook. This was not implemented as it was felt to be an appropriate place prior to the first imagery exercise, but signposting to this chapter was provided prior to experiential exercises in other chapters.

**Identified as future considerations when CMT-PAC is tested.** CPs discussed possibilities for how CMT-PAC is used in practice, such as an adjunct to group therapy, to support clinician confidence when planning individual CMT therapy sessions with the target population group, and the possibility of CMT-PAC guided support being facilitated by trained parents into neurodiversity hubs or parent social media groups. CPs discussed research areas of interest including the impact of CMT-PAC offered as a waitlist intervention when parents are awaiting their child's autism assessment, and the impact of CMT-PAC on number of referrals for parent

consultations. CPs shared ideas for possible alternative intervention formats, including use of video or a mobile application, to aid accessibility.

### 3.2 Example Feedback from Parents

Feedback received were coded using the FRAME nature of adaptations section. The below provides example commentary from different FRAME codes for nature of adaptations, retrieved from parents, shown below in Tables 5 and 6.

**Table 5**

*Examples of Feedback During First Focus Group by Category*

| <b>Feedback category</b>                   | <b>Comment</b>                                                                                                                                                                                                                                                                   | <b>In relation to</b>                                           |
|--------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------|
| <b>Removing/<br/>Skipping<br/>Elements</b> | <i>Rachel: you don't need to talk about how people's brains work. [...] the automatic nervous system and the sympathetic nervous system, you know, and I'm like why do we need to know things like that really?</i>                                                              | Workbook Part I 'Understanding our mind'.                       |
| <b>Re-ordering<br/>Modules</b>             | <i>Rachel: I think that's what it needs to focus on, doing the therapy with the option of learning more about it alongside. Um, at the moment it's focused on the theoretical aspect of it, with the actual therapy on the side. But it needs to be the other way round</i>      | Audio track exercise placement at the end of original workbook. |
| <b>Shortening/<br/>Condensing</b>          | <i>Mo: maybe it could be a bit shortish paragraphs, maybe? Yeah, I don't know or, a bit more, um, more pictures or things like that.<br/>Rachel: if you can reduce the language and bullet pointed a bit more and organised it a bit better, I think every page is too long.</i> | Workbook Part I.<br>Entire workbook.                            |

| Feedback category              | Comment                                                                                                                                                                                                                                                                                                                                                               | In relation to                                  |
|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------|
| <b>Spreading</b>               | <i>Jane: Yeah, I think breaking it down's definitely better.</i>                                                                                                                                                                                                                                                                                                      | Experiential exercise placement.                |
| <b>Tailoring/<br/>Refining</b> | <i>Jane: It was also talking about students and stuff, so it was, that kind of turned me off a bit because I thought, I want this to be talking to me as a parent, and me as an autistic parent as well, not as a, sorry as a parent of an autistic child, and there was nothing really in there that was talking to me in that sense, it was very, very general.</i> | Workbook Part I, 'Understanding your emotions'. |
|                                | <i>Rachel: I think it needs, the very first to starting off with very poignantly put about how this relates or how it could be applied to meet a parent of an autistic child, how is it relevant, you know, where's the connection, there wasn't like a direct connection mentioned.</i>                                                                              | Introduction.                                   |
|                                | <i>Rachel: I think that the actual instruction for carrying it out for what you should do could be a bit, a bit more descriptive maybe, than it is at the moment, I know it has to be open to you being able to do it when you can, but it's kind of like that two week programme, then you've finished, okay so am I compassionate now? (laughs)</i>                 | Workbook Part IV: The Actual Practices.         |
|                                | <i>Jane: It might actually be helpful to have a suggested sort of timetable if you like, or something like that at the beginning maybe, just to say 'well we'd recommend that you take this amount of time each week, or you could do it this way' just as a guide and people can sort of flex it how they want it.</i>                                               | Introduction                                    |

| Feedback category | Comment                                                                                                                                                                                                                                                                                              | In relation to                                      |
|-------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------|
| <b>Format</b>     | <p>Rachel: <i>They use lots of big words to describe very simple concepts and I think that also puts you off, there's no need for all of that. You know, not everyone who reads it is from a medical background or a university level education, so why promote it to those sorts of people?</i></p> | <p>Workbook Part III: Preparation for Practice.</p> |
|                   | <p>Mo: <i>Maybe do some colour-coding for the, like the breathing and all that?</i></p>                                                                                                                                                                                                              | <p>Entire workbook.</p>                             |
| <b>Format</b>     | <p>Jane: <i>I think definitely prefer rather than it just being a written document, a video, somebody talking um rather than reading, using my read aloud software.</i></p>                                                                                                                          | <p>Workbook format.</p>                             |
|                   | <p>Rachel: <i>I think that in-person support, (sigh) whether that's that they come into your home, or whether they do it, um in the different ways of contacting you whether it's by email or whatever, it's going to make you more likely to take part in this.</i></p>                             | <p>Use of guided support.</p>                       |
| <b>Personnel</b>  | <p>Rachel: <i>I think that you can't write something for parents of autistic children if you are not a parent of an autistic child.</i></p>                                                                                                                                                          | <p>Intervention Adaptation Team.</p>                |
| <b>Population</b> | <p>Rachel: <i>You would be more likely to get engagement with it prior to diagnosis, because it's for everybody, um, and I think part of the sort of selling point of it could be that it is for parents of neurotypical or neurodiverse children.</i></p>                                           | <p>Target Population Group.</p>                     |



**Table 6**

*Examples of Feedback During Second Focus Group by Category*

| <b>Feedback category</b>      | <b>Comment</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | <b>In relation to</b>                                                                                                                                             |
|-------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Adding Elements</b>        | <i>Claire: The benefits where you're grateful, you know when you write down three things a day, that's been proven to be um, really positive for mental health, so like, kind of incorporating that within this letter format is a suggestion.</i>                                                                                                                                                                                                                                                                                           | Chapter Six<br>'Compassionate Letter Writing'.                                                                                                                    |
| <b>Loosening Structure</b>    | <i>Rachel: if we just make it clear that if you miss a week or, you know that kind of thing, you've not got to restart the whole thing, or, it's not something that won't work if you don't do it in order every week, um, then I think it's reasonable</i>                                                                                                                                                                                                                                                                                  | A bit about this book, suggested timetable.                                                                                                                       |
| <b>Shortening/ Condensing</b> | <i>Mo: We could have some bullet points after this point about different benefits for ourselves, and then all the different benefits, it was three or four bullet points, that would've been good, but I don't know, because I feel that the paragraph is quite long.</i>                                                                                                                                                                                                                                                                    | Chapter Four,<br>'Benefits of Compassion'.                                                                                                                        |
| <b>Tailoring/ Refining</b>    | <i>Claire: it would be helpful for me personally to have labels on the circles or a key diagram maybe like right next to it?</i><br><i>Mo: The colours should be a bit different, um, the green colour could be a bit more brighter.</i><br><i>Rachel: What about clouds? [...] I just think that visually looking at it, doing something so that it looks, the visuals look calmer.</i><br><i>Claire: I would like some sort of example or scenario again, I just really, that really helps me, rather than just kind of trying to make</i> | Chapter One,<br>Three Emotion Circles.<br>Chapter One,<br>Three Emotion Circles.<br>Chapter Two,<br>'You're Your Own Worst Critic'.<br>Chapter Two,<br>'How Might |

| <b>Feedback category</b> | <b>Comment</b>                                                                                                | <b>In relation to</b> |
|--------------------------|---------------------------------------------------------------------------------------------------------------|-----------------------|
|                          | <i>sense of things with how do we be more compassionate, how do we implement that, in a certain scenario.</i> | Compassion Help?'     |

### 3.3 Example Feedback from CPs

The below provides example commentary from different FRAME codes for nature of adaptations, retrieved from CPs, and provided below in Tables 7 and 8.

**Table 7**

*Examples of Feedback During Phase Three by Category*

| <b>Feedback category</b>      | <b>Comment</b>                                                                                                                                                                                                                                                     | <b>In relation to</b>                       |
|-------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------|
| <b>Adding Elements</b>        | <i>Jan: I wondered if having a couple of other examples and a little bit of their story at the beginning might be useful? If these stories were followed through they could be used to help with the exercises to illustrate overcoming potential road blocks.</i> | Introduction, addition of story characters. |
|                               | <i>Polly: I did wonder about a compassionate object exercise so parents have something they can carry around with them?</i>                                                                                                                                        | Workbook exercises.                         |
|                               | <i>Shona: Could be an idea to introduce chronic stress idea here.</i>                                                                                                                                                                                              | Chapter One, Tricky brain.                  |
| <b>Lengthening/ Extending</b> | <i>Polly: Maybe chunk this bit as it has a lot of important info in. You could put a bit about what happens to animals and then do the human bit?</i>                                                                                                              | Chapter One, Tricky brain.                  |

| <b>Feedback category</b>   | <b>Comment</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | <b>In relation to</b>                                                                          |
|----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|
| <b>Removing Elements</b>   | <i>Polly: Do the references need to be in a for a parent workbook? May make it seem more formal?</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Chapter Four, 'Benefits of Compassion'                                                         |
| <b>Re-ordering Modules</b> | <i>Jan: It did cross my mind that this could be the chapter that sells the intervention and whether bits of this could come earlier? I acknowledge that chapter one defines compassion and chapter 2 related this to parenthood which is key, - the audience are parents first and this really relatable stuff might help them connect to the work.</i><br><i>Jan: I think this preparation for practice stuff is very helpful and relevant to the other exercises, I wonder if some of this could be put in earlier so that a general sense of preparation for practice can be encouraged for all exercises? Maybe as an intro pre chapter 1.</i> | Chapter Two, Relating Compassion to Parenthood<br><br>Chapter Three, Preparation for Practice. |
| <b>Spreading</b>           | <i>Polly: A lot of ideas have been introduced in a short space of time and I wonder if there is anyway to spread this out a little so the first section is less dense with new information?</i><br><i>Polly: Is it worth breaking this into 2 exercises? So you consolidate developing the compassionate self before doing the following "Now to develop this practice a step further I'd like you to imagine you're watching a video of yourself....."</i>                                                                                                                                                                                        | Chapter One<br><br>Chapter Three Exercise, 'Developing your Compassionate Image'               |
| <b>Tailoring</b>           | <i>Jan: It may be helpful to include a rationale for using the term autistic and an acknowledgment that some people may use other terminology.</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | Workbook introduction.                                                                         |

| <b>Feedback category</b> | <b>Comment</b>                                                                                                                                                                                          | <b>In relation to</b>                  |
|--------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------|
|                          | Jan: <i>I wonder if the "it's not your fault" might be good to be made more impactful in the text/key points, bigger font, bolder?</i>                                                                  | Chapter One, Tricky brain              |
|                          | Polly: <i>I would probably make some of the language less formal and take out scientific terms (like fight, flight, freeze) unless they are explained to people using more simple language.</i>         | Chapter One, Tricky brain.             |
|                          | Shona: <i>I'm wondering how the steering groups responded to the level of jargon used? This could be simplified if needed.</i>                                                                          | Chapter One, 'What is compassion?'     |
|                          | Tara: <i>I like these examples. I wonder if they're presented in the most helpful/accessible way. Not sure if the arrows are too big.</i>                                                               | Chapter One, Unhelpful thinking loops. |
| <b>Format</b>            | Polly: <i>Have you considered using videos as well as audios, such as videos of the posture stuff as it will be easier for parents to process.</i>                                                      | Workbook format                        |
|                          | Tara: <i>Also think CFT groups can work well so parents can tap into the shared experience. This would also help with the practice of directing compassion to others and then turning that inwards.</i> | Intervention format                    |

*Note: CFT = Compassion Focused Therapy.*

**Table 8**

*Examples of Feedback During Third Focus Group by Category*

| <b>Feedback category</b>   | <b>Comment</b>                                                                                                                                                                                                                                                        | <b>In relation to</b>                                                               |
|----------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------|
| <b>Adding Element</b>      | Shona: <i>It could be, like, an option, couldn't it? You could write a letter, some people might find that quite off-putting because not everybody enjoys writing, and having something concrete might work for some people where words work for another.</i>         | Workbook exercises, adding compassionate object exercise.                           |
| <b>Loosening Structure</b> | Polly: <i>Just saying you know, we get that for families that you know, there's times where it just feels crazy and so busy, and whether almost like they can put a pause on it like a breaker and come back to it?</i>                                               | Workbook introduction.                                                              |
| <b>Re-ordering Modules</b> | Tara: <i>Bringing the parenting bit at the beginning, to help get that buy in, I think yeah, that would make sense to swap those bits over.</i>                                                                                                                       | Swapping Chapters One and Two.                                                      |
| <b>Spreading</b>           | Jan: <i>I think if you could weave it through, that um, that might make it more accessible.</i>                                                                                                                                                                       | Chapter One, psychoeducation.                                                       |
| <b>Tailoring</b>           | Tara: <i>What about a footnote?</i><br><br>Jan: <i>I think yeah, if you did include something like that, then having a kind of um, sort of one foot in the compassionate message and the other in a more practical um, so it doesn't come across as an insincere.</i> | Chapter Four, References.<br><br>Modelling compassion at beginning of each chapter. |
| <b>Format</b>              | Polly: <i>...Troubleshooting videos for parents, and ask really common</i>                                                                                                                                                                                            | Workbook format, additional videos.                                                 |

| <b>Feedback category</b> | <b>Comment</b>                                                                                                                                                                                                                                                                               | <b>In relation to</b>                                              |
|--------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------|
| <b>Setting</b>           | <i>questions, or things that they want to know more about.</i>                                                                                                                                                                                                                               | Intervention setting.                                              |
| <b>Setting</b>           | <i>Shona: I'm just imagining, like, how say if we were to use this resource, could it be something that we offer as a waiting list intervention.</i>                                                                                                                                         | Intervention setting.                                              |
| <b>Setting</b>           | <i>Tara: Having almost like, groups of, something where you can join a Facebook group or whatever it is, where there's other people doing it at the same time so you can get that kind of accountability check in type of thing, you know almost like you'd have with a book club.</i>       | Intervention setting.                                              |
| <b>Evaluation</b>        | <i>Polly: It might be worth looking so that as you distribute the workbook if you know, as things evolve, how you want to get the buy in from clinicians to continue to data collect on the resource itself, so it will help to inform your kind of continual development.</i>               | Ongoing intervention evaluation methods.                           |
| <b>Implementation</b>    | <i>Shona: there's always going to be some groups of people that don't have that sort of way of thinking, or different hurdles for different people, and I think it's just maybe acknowledging that and offering options, or like 'if this isn't for you, maybe try something like this?'</i> | Considerations for implementing intervention to target population. |

### **3.4 Account of Observations Across Focus Groups from Facilitators**

There were notable differences in responding style within the two PAC focus groups. Immediately after the focus group meetings, the facilitators met to discuss their observations relating to the content and process of the group meetings. The following provides an account of the themes observed across FG1 and FG2, with subjective impressions noted by the lead author, and considerations regarding how these differences influenced the FA approach.

During FG1, all participants expressed largely negative feedback about the existing CMT resource as a whole. Although attempts were made by the facilitators to seek specific advice regarding PAC amendment suggestions, the participants' responses were often broad in nature, such as responding that the entire workbook required rewriting when facilitators asked for examples of sections that could be shortened or condensed. Two of the three attendees spoke at length whilst describing their negative opinions about the workbook, and they related this to their negative experiences navigating health services and parenting. The length of their contributions could be interpreted as a communication difference related to their self-disclosed neurodivergence but may also signal that their contributions were influenced by an emotional response to the general CMT resource for parents, or their desire for the needs of the PAC population to be heard by those in the field of Clinical Psychology. As a result, the overall nature of FG1 became more open and unstructured than the pre-developed interview schedule, where attendees commented on areas of contention regarding the CMT resource in no particular order. To navigate this, the lead facilitator was responsive to facilitating the group flexibly, to encourage rich discussion between all participants and the development of rapport with the researchers. However, facilitators still brought all questions in the interview schedule to the group in an order that best fit with the existing flow of conversation. In attempt to re-balance the frequency of contributions between the three participants, the facilitator was required to make multiple active attempts to bring the third attendee into the discussion, by offering space for them to contribute to existing topic areas or bring new ideas for discussion.

In contrast, the responding style during FG2 was more positive and followed the structure of the pre-determined interview schedule, although questions were broadened to account for new participants that had not seen the original CMT resource. The frequency and length of participant contributions appeared more balanced between attendees, but it was observed that there were greater silences

amongst the group and a less discussion between participants without ongoing active prompting from the researcher (e.g., “what do others think about [PARTICIPANT]’s idea?”). The facilitator welcomed silences to support participant’s processing time and enable opportunities for further participant-led discussions, but participants occasionally commented that the resource was acceptable in its current format and did not provide any further commentary.

As a result, the lead author considered whether the differences in response styles and overall natures of the focus groups could reduce the tenability of the FA to be performed. The Framework method can be useful to manage large datasets, to obtain a holistic descriptive overview of all data collected, but it is not recommended for highly heterogeneous data, defined as data that does not cover similar topics or key issues, and so would therefore be classed as uncategorisable (Gale et al., 2013). In order to assess whether the FA could accommodate the focus group data in the present research, the lead author returned to the second research question to ensure that this remained at the forefront of the planned FA process. As a result of reading all the focus group transcripts during the data familiarisation phase, it was highlighted that there were initial relevant themes that were prevalent across the entire dataset, that were felt to appropriately answer the second research question. These themes supported the construction of an initial coding framework, and the FA was continued and successfully completed as planned.



### 3.5 Adaptation of the CMT-PAC workbook

Table 9 provides several example intervention components that were adapted over the four feedback phases, with reference to the relevant literature or guidance followed.

**Table 9**

*Examples of How Compassionate Mind Training for Parents of Autistic Children (CMT-PAC) Was Adapted*

| Target adaptation                                                     | What guidance was followed?                                                                                                                                                                                                                                                                                                                                                                                                                                             | Comparison to the original resource                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|-----------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>Psychoeducation regarding CMT theory: unhelpful thinking loops</i> | <ul style="list-style-type: none"> <li>• Simplified language and increased readability as recommended within self-help good practice guidance (Baguley et al., 2010).</li> <li>• Diagram adapted from existing published CMT self-help materials to explain unhelpful thinking loops to maintain theoretical coherence (Irons &amp; Beaumont, 2017).</li> <li>• Autism-specific example used to increase relevance to PAC (World Health Organization, 2024).</li> </ul> | <ul style="list-style-type: none"> <li>• Split into smaller sections with subheadings; tricky brain; what happens in animals' brains; what happens in our human brains; example.</li> <li>• Use of diagram to show 'old brain' and 'new brain' sections, with coloured text to share how each work.</li> <li>• Used diagram and imagery to show an example unhelpful thinking loop using a common parenting scenario for PAC. Linked to story characters highlighted at beginning of workbook.</li> </ul> |

| Target adaptation                                                  | What guidance was followed?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Comparison to the original resource                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|--------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>De-shaming parenting experiences: children’s ability levels</i> | <ul style="list-style-type: none"> <li>Substantial variability in developmental milestone attainment in autism, therefore not applicable to target population (Kuo et al., 2022).</li> <li>Replaced with common autistic traits (NHS England, 2022) using neuro-affirmative language (Hartman et al., 2023) to increase relevance to PAC (World Health Organization, 2024).</li> <li>Functions to de-shame parenting challenges; theoretically coherent with initial step in CMT (Gilbert &amp; Procter, 2006).</li> </ul> | <ul style="list-style-type: none"> <li>Reduced formality of language using MS Word accessibility function.</li> <li>Removed list of age-related developmental milestones.</li> <li>Added common traits seen in autistic children using diagram format: colour coded by type of difference with key, grouped by colour. Included “differences in age when meeting developmental milestones”.</li> <li>Added disclaimer that some child differences may or may not be relatable to all PAC and validated differing recipients’ experiences.</li> </ul> |
| <i>Experiential practice: CMT exercises</i>                        | <ul style="list-style-type: none"> <li>Advocation of regular practice is theoretically consistent with CMT, including daily use (Irons &amp; Heriot-Maitland, 2021; McEwan &amp; Gilbert, 2016).</li> </ul>                                                                                                                                                                                                                                                                                                                | <ul style="list-style-type: none"> <li>CMT exercises placed at the end of each workbook chapter, rather than together as an appendix.</li> <li>Pre-introduction to workbook added with suggested timetable with</li> </ul>                                                                                                                                                                                                                                                                                                                           |

| Target adaptation | What guidance was followed?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Comparison to the original resource                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|-------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                   | <ul style="list-style-type: none"> <li>• Signposting for advice from a health professional prior to body-based exercises recommended to reduce risk of adverse effects (Cramer et al., 2019).</li> <li>• Evidence-based interoceptive awareness strategies (Goodall, 2021) added to support recipient troubleshooting.</li> <li>• Ending imagery exercises through noticing the breath is theoretically consistent with CMT (Kolts, 2016).</li> <li>• Improved readability via simplified language and diagram use to support information processing as recommended in self-help good practice guidelines (Baguley et al., 2010).</li> <li>• Reflective writing can effectively support continuous learning to strengthen practice (Olmos-Ochoa et al., 2021) and can be used</li> </ul> | <p>timeframes to complete daily practice.</p> <ul style="list-style-type: none"> <li>• Prior to first experiential exercise, signposting to troubleshooting information is provided and stumbling blocks are normalised during practice.</li> <li>• Addition of activities to support interoception prior to body-based CMT practices, linking to neurodivergent story character’s experience.</li> <li>• Addition of diagram to show what is meant by a compassionate posture, with a comparison diagram.</li> <li>• Addition of disclaimer prior to first exercise regarding physical health implications related to posture changes and breathing exercises. Advice provided to speak to General Practitioner before attempting exercises if recipients have any pre-existing medical conditions.</li> </ul> |

| Target adaptation                                                                                        | What guidance was followed?                                                                                                                                                                                                                                                                                                                                                           | Comparison to the original resource                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|----------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                          | <p>in compassion-based interventions (e.g., Sirois et al., 2019).</p> <ul style="list-style-type: none"> <li>• Compassionate letter writing or objects can be used during CMT (Gilbert &amp; Procter, 2006) and provide a transitional object with a tangible method for recipients to access compassionate skills developed through practice (Lucre &amp; Clapton, 2021).</li> </ul> | <ul style="list-style-type: none"> <li>• Scripts for audio tracks highlighted within green text boxes with ear symbol to indicate use of audio track, if accessible to recipients.</li> <li>• Language simplified, e.g., from “diaphragm” to “stomach”.</li> <li>• Ending of exercises changed from directions to think about nothing, to instead re-focus attention on breathing.</li> <li>• Addition of empty text boxes to encourage reflective writing after exercises.</li> <li>• Addition of compassionate letter writing and compassionate object exercises in chapter six.</li> </ul> |
| <p><i>Troubleshooting information and normalising difficulties: Preparation for practice chapter</i></p> | <ul style="list-style-type: none"> <li>• Imagery defined as occurring in any sensory modality rather than visual format alone, as stated by Naismith et al. (2019).</li> <li>• Reflective writing can effectively support continuous learning to strengthen practice</li> </ul>                                                                                                       | <ul style="list-style-type: none"> <li>• Addition of ‘quick note’ to define what is meant by imagery.</li> <li>• Addition of reflective exercise for PAC to write their initial thoughts regarding developing a compassionate self.</li> <li>• Troubleshooting tips re-formatted using bullet</li> </ul>                                                                                                                                                                                                                                                                                      |

| Target adaptation                          | What guidance was followed?                                                                                                                                                                                                                                                                                                                                                                              | Comparison to the original resource                                                                                                                                                                                                                                                                                                                                                                                      |
|--------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                            | <p>(Olmos-Ochoa et al., 2021).</p> <ul style="list-style-type: none"> <li>• Recommendations for common worries prior to practice adapted from Kolts (2016).</li> <li>• Improved readability via formatting to support information processing as recommended in self-help good practice guidelines (Baguley et al., 2010).</li> </ul>                                                                     | <p>points and speech bubbles incorporating story characters.</p> <ul style="list-style-type: none"> <li>• Addition of troubleshooting advice for becoming disrupted midway through CMT practice.</li> <li>• Addition of troubleshooting advice for PAC with beliefs that they don't have the compassionate qualities required.</li> </ul>                                                                                |
| <i>Therapeutic ending: End of workbook</i> | <ul style="list-style-type: none"> <li>• Reflection of strengths and accomplishments discovered is recommended to facilitate a therapeutic ending (Poole, 2021).</li> <li>• Structure of compassionate ending letter in workbook adapted from existing CMT self-help workbook to model compassion to future recipients whilst maintaining theoretical coherence (Irons &amp; Beaumont, 2017).</li> </ul> | <ul style="list-style-type: none"> <li>• Appendices are removed, but recommended further reading and key texts are referenced.</li> <li>• Reflective spaces incorporated to prompt recipients to write about their learning from the intervention.</li> <li>• Addition of a brief letter from lead researcher to compassionately acknowledge the ending of the intervention and encourage continued practice.</li> </ul> |

*Note:* CMT = Compassionate Mind Training; PAC = Parents of Autistic Children.

### 3.6 Example Adaptation Process

The following provides an example to show how CMT-PAC was adapted during the four feedback phases. Figure 2 shows how compassion was defined within the original resource. PAC feedback during FG1 included a request that the length of written sections was reduced through use of bullet points where applicable, and simplification of language. Participants also requested that potentially irrelevant references were removed, such as examples regarding discussions with a partner or taking an exam, as these were hypothesised to potentially reduce engagement by future study participants. Finally, participants questioned the purpose of learning the theoretical background of the approach. As a result, adaptations involved use of a list to highlight the six attributes of compassion, as described by Gilbert (2010). The lengthy written example was removed as requested. Finally, a small paragraph was included to provide the rationale more clearly for learning about this, including how this relates to the following sections (see Figure 3). PAC during FG2 provided positive feedback about the changes made and no further amendments were suggested.

CP written feedback during phase three requested further simplification in language regarding the six attributes of compassion, to broaden the range of PAC with different learning needs that may be able to engage with the workbook. Furthermore, it was requested that the subheadings made clearer distinctions between what compassion is and isn't, to support future recipients' information processing. Finally, CPs requested that a specific example was re-added to illustrate how compassion is associated with courage and strength. Although this was not specifically requested within FG2, it was acknowledged that specific examples were requested by attendees for elsewhere in the workbook, so this was facilitated during refinement (see Figure 4).

Finally, CP feedback during FG3 included a recommendation to switch the first and second workbook chapters (understanding compassion, and the experience of parenting) to increase fit with PAC future recipients by making the intervention appear relatable to the target population from the outset. Therefore, the placement of this section moved to be at the end of the new chapter one, following information regarding challenges in parenting. As a result, minor formatting changes were made to improve presentation, as it now flowed over two workbook pages (see Figure 5). Further

rationale was moved to be integrated into the final section of chapter one; “*how might compassion help?*” as shown in the final CMT-PAC resource<sup>69</sup>.

## Figure 2

### *Definition of Compassion in Original Resource*

**What is compassion?**

Compassion is commonly defined as “*a sensitivity to suffering in self and others with a willingness to try to alleviate and prevented it*”. If you look carefully at this definition you will see there are two aspects to compassion. The first is the ability to notice and engage with things that are upsetting or distressing. The second is the ability to do things and learn and practice ways of being that are helpful both in the short term and the long term. Just like becoming physically fit, compassion involves understanding the relevant exercises needed (e.g. push-ups work your arms, chest, core, hips and legs) and then practicing them to obtain benefits (e.g. if you don’t actually engage with push-ups then you won’t observe any of the physical benefits!).

Some people misunderstand compassion and feel it’s about just being ‘kind’ or is soft or weak. Some even can feel that being compassionate with oneself is somewhat of a luxury or a bit of a self-indulgence. But actually compassion is a way of helping us have the courage to deal with the struggles we face in our lives. Think about this. Supposing you have something difficult to do like an exam you’re anxious about, or something worrying such having to go to hospital for some tests or perhaps even more painfully, going through a divorce/break-up. Most of us would rather avoid these things. Imagine a very compassionate friend helping you. How would they be with you? Well, listening, understanding and being supportive are important aspects, but also *encouraging* you to do the things you may not want to do is vital. For example, encouraging you to do that study for the exam or having that difficult conversation with a partner, are things we need to do. The one thing they wouldn’t do is to advise you to avoid things or just to make it easy on yourself. (For example, “*if it’s difficult to study for the exam, then maybe you shouldn’t do it? Maybe you should skip it*” are examples of advice you wouldn’t hear from a true friend). Your compassionate friend will try to support and help you in any way they can to give you *the courage* to face what you need to face (for example, “*I understand that it’s going to be hard and frustrating to study for that exam, but I know you can do it, and you really want to graduate and this will help you become what you’d like to be.*”)

So the first thing we learn about compassion is that compassion is not about weakness at all; indeed, when times are hard compassion can really help us get through them. So compassion means we are able to go face up to difficulties and genuinely work out how best to be helpful.

*(developed and used by Kirby et al., 2023)*

<sup>69</sup> See Appendix X for final CMT-PAC resource.

### Figure 3

*Adapted Version Following Focus Group One*

#### **What is compassion?**

A definition of compassion is “a sensitivity to potential suffering in both self and others, with a willingness to prevent and reduce it”. Researchers suggest that compassion is built up from six different qualities:

1. **Wisdom:** Learning from our own personal experiences as we go through life and engage with the world, to understand what it is to be human; to struggle, to have rage, desires, and joy.
2. **Maturity and Insight:** Understanding the nature of life's difficulties, acknowledging that suffering is a universal part of being a human and that everyone will experience this at some point or another.
3. **Strength:** We learn to endure and tolerate this suffering, but we can also protect and defend from suffering if needed.
4. **Warmth and Kindness:** We are empathetic and supportive to help us to work to feel better about ourselves.
5. **Non-judgemental and Non-condemning:** We view situations without judgement or feeling negatively about it, but instead look at situations with an open mind.
6. **Sense of Responsibility:** A desire to help or change in positive ways.

Some people misunderstand compassion and feel it's about just being 'kind' or is soft or weak. Some might even feel that being compassionate with themselves is a bit of a self-indulgence. But compassion is a way of helping us have the courage to deal with the struggles we face in our lives. So, the first thing we learn about compassion is that compassion is not about weakness at all; when times are hard, compassion can really help us get through them. Compassion helps us to understand, recognise and face difficulties with great strength and resilience.

The next part of this chapter talks about how our minds have evolved over time, and why we have the range of emotions, passions, and desires.

Becoming aware of this is a very important first step to being able to stand back and recognise that we did not create or choose to have these experiences. This gives us greater power in understanding what our compassionate self is up against!



## Figure 4

*Adapted Version Following Written Feedback from Clinical Psychologists*

**What compassion is...**

Compassion has two main parts: 1. being aware of the possible suffering in us and others, and 2. being ready to do something about it, to prevent it from happening or to make things a little easier if it's already happened. Researchers suggest that compassion is built up from six different qualities:

1. **Wisdom:** Learning from our own personal experiences as we go through life.
2. **Maturity and Insight:** Knowing that highs and lows are a very normal part of being human.
3. **Strength:** Being able to stand up for ourselves and shield against suffering if needed, but also learning how to tough it out and tolerate this suffering sometimes too.
4. **Warmth and Kindness:** We're understanding and here to support each other so that we can all feel better about ourselves.
5. **Non-judgemental and Non-condemning:** We don't judge or hate on stuff. We just keep an open mind and see situations for what they are.
6. **Sense of Responsibility:** A strong urge to make a difference and help others in a good way.

**What compassion isn't...**

Some people think that compassion is all about just being kind, or is seen as 'soft' or 'weak', or even a bit indulgent. But compassion actually helps us gather the courage to face the challenges in our lives.

Compassion isn't a sign of weakness; in fact, it can truly help us when times get hard. Compassion helps us to understand, recognise and face difficulties with great strength and resilience.


The next part of this chapter talks about how our minds have evolved over time, and why we have all these different emotions, passions, and desires. Understanding this is super important, because it helps us realise that we don't consciously choose to have these experiences. Once we see this, we can better understand the challenges our compassionate self faces.

**Example:**

Ryan saw his daughter pulling at a shelf. This was making a heavy box at the top begin to wobble. It looked like it might fall onto her.

Ryan quickly shouted STOP and ran over to move her away. This put him in danger of the falling box too, but he did it to protect his daughter anyway.

This was a compassionate way of responding: he saw she might potentially suffer, so he took action to prevent this.



## Figure 5

*Adapted Version Following Focus Group Three*

**What compassion is...**

Compassion has two main parts: 1. being aware of the possible suffering in us and others, and 2. being ready to do something about it, to prevent it from happening or to make things a little easier if it's already happened. Researchers suggest that compassion is built up from six different qualities:


1. **Wisdom:** Learning from our own personal experiences as we go through life.
2. **Maturity and Insight:** Knowing that highs and lows are a very normal part of being human.
3. **Strength:** Being able to stand up for ourselves and shield against suffering if needed, but also learning how to tough it out and tolerate this suffering sometimes too.
4. **Warmth and Kindness:** We're understanding and here to support each other so that we can all feel better about ourselves.
5. **Non-judgemental and Non-condemning:** We don't judge or 'hate on' stuff. We just keep an open mind and see situations for what they are.
6. **Sense of Responsibility:** A strong urge to make a difference and help others in a good way.

**Example:**

Ryan saw his daughter pulling at a shelf. This was making a heavy box at the top begin to wobble. It looked like it might fall onto her.

Ryan quickly shouted STOP and ran over to move her away. This put him in danger of the falling box too, but he did it to protect his daughter anyway.

This was a compassionate way of responding: he saw she might potentially suffer, so he took action to prevent this.



**What compassion isn't...**

Some people think that compassion is all about just being kind or is seen as 'soft' or 'weak', or even a bit indulgent. But compassion helps us gather the courage to face the challenges in our lives.

Compassion isn't a sign of weakness; in fact, it can truly help us when times get hard. Compassion helps us to understand, recognise and face difficulties with great strength and resilience.

### 3.7 Further Example Participant Quotes from Framework Analysis

Additional quotes from all focus groups to illustrate the key concepts are presented below in Table 10.

**Table 10**

*Additional Quotes to Illustrate Final Themes*

| <b>Theme</b>     | <b>Additional Participant Quotes</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Role as a Parent | <p><i>most people that are trying to get their children diagnosed have already been through a lot of issues and a lot of trials and tribulations –Jane (parent, FG1)</i></p> <p><i>if your child doesn't go out, or your child doesn't want to go anywhere, then neither will you. –Rachel (parent, FG1)</i></p> <p><i>it's the sort of childcare issues that you're gonna have –Rachel (parent, FG1)</i></p> <p><i>I think if you had the exercises as the back which the previous, I think, what like Josie says you wouldn't, you wouldn't, you wouldn't look at them, because you'd just think 'oh god' –Olivia (parent, FG2)</i></p> <p><i>quite often you will, you're more likely, or for me anyway, um, are more likely to try and support someone else rather than support yourself –Rachel (parent, FG2)</i></p> <p><i>we get that for families that [...] there's times where it just feels crazy and so busy, and whether almost like they can put a pause on it like a breaker and come back to it? It's not a sense of failing as a parent, it's part of the course of trying to engage in something alongside all the trials and tribulations of parenting children, and parenting children that might have</i></p> |

| Theme                  | Additional Participant Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                        | <p data-bbox="555 282 1251 365"><i>particular struggles day to day as well –Polly (Clinical Psychologist, FG3)</i></p> <p data-bbox="515 434 1294 566"><i>as a parent anyway, you're not going to prioritise helping yourself because you just don't, your priority is helping your children –Rachel (parent, FG1)</i></p> <p data-bbox="496 636 1313 768"><i>everybody who's a parent is, has very limited time especially if you're a working parent as well, you know you have very limited time –Rachel (parent, FG1)</i></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| Parental Mental Health | <p data-bbox="496 786 1310 1021"><i>The research shows that like, they're some of the most stressed parents, aren't they? And I guess could really benefit from a CFT approach but on a practical sense, can then mean it feels like you just haven't got the headspace to access something –Polly (Clinical Psychologist, FG3)</i></p> <p data-bbox="496 1090 1313 1274"><i>I think the intrusive thoughts are a big one actually, and like, yeah that can be quite overwhelming and just another stressor like 'why can't I do this? I keep having these bloody thoughts popping into me' –Jane (parent, FG1)</i></p> <p data-bbox="496 1344 1313 1527"><i>sometimes, it's, you're failing at what you're doing, you're failing as a parent, your child is not acting how it's supposed to be doing, so it can be very difficult to do something and think "I can't even do that either" –Rachel (parent, FG1)</i></p> <p data-bbox="496 1597 1310 1729"><i>not doing it when we say you should do it, that makes you feel like a failure, [...] and you often have those feelings anyway – Rachel (parent, FG1)</i></p> <p data-bbox="496 1798 1313 1982"><i>by the time you're actually asking professionals for help, by the time you're going for that, you've already been through a lot, and I'm, I just wasn't quite sure when the time would be for this because, you're either at crisis point which [...] you're not</i></p> |

| Theme                      | Additional Participant Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                            | <p data-bbox="491 277 1313 465"><i>gonna have time to read this because you're literally just going through hell and you've got meltdowns all the time, and you're just living in absolute misery and [...] torture –Jane (parent, FG1)</i></p> <p data-bbox="491 533 1313 768"><i>it reminds me of school, when I was in school as a child and the board, they'd have those cut-outs like that, and in much more bright colours with things shoved on the boards, so that's like almost - I didn't have the best time in school – triggering for me, seeing that back there like that –Claire (parent, FG2)</i></p> <p data-bbox="491 835 1313 1070"><i>what you might find is that as soon as you develop a compassionate image, then that might bring all sorts of well, why didn't I have that? Why didn't anyone do this for me? And that can open a whole other can of worms –Shona (Clinical Psychologist, FG3)</i></p> <p data-bbox="491 1137 1313 1227"><i>it's not that CFT can't be used for trauma, it can, it just, it's recognising that it can open up other things. –Shona (CP, FG3)</i></p> |
| Services around the Parent | <p data-bbox="491 1234 1313 1379"><i>I think especially when the diagnosis pathway is so long [...] that by the time you reach the diagnosis you are probably nearing crisis point, possibly. –Rachel (parent, FG1)</i></p> <p data-bbox="491 1447 1313 1581"><i>until you've got that diagnosis officially then you haven't got an official autistic child, so that can also prevent you accessing support until you've got the autism label –Rachel (parent, FG1)</i></p> <p data-bbox="491 1648 1313 1738"><i>you're waiting for that label to get access to open more doors, but then there's a lot of closed doors –Jane (parent, FG1)</i></p> <p data-bbox="491 1805 1313 1939"><i>you have a diagnosis, you know, you have a child and then it's kind of like go away and help yourself. You are not in that position to go away and help yourself –Rachel (parent, FG1)</i></p>                                                                                                                                                                                                                      |

| Theme                            | Additional Participant Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|----------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                  | <p data-bbox="501 286 1315 517"><i>when my daughter got her diagnosis, because the NHS had outsourced it to a private company, a lot of the recommendations they put were the NHS, I was like “where do I get all these services?” and they were like “they don’t exist” and I thought, oh great. –Jane (parent, FG1)</i></p> <p data-bbox="501 584 1315 667"><i>I’ve not seen main providers offer CFT and I think it’s a really big gap –Polly (Clinical Psychologist, FG3)</i></p> <p data-bbox="501 734 1315 920"><i>As an intervention where a pathology could exist, and has met a service criteria, to make that a universal offer seems like a no brainer really, like, if you can make it accessible, why wouldn’t you? –Shona (Clinical Psychologist, FG3)</i></p> <p data-bbox="501 987 1315 1272"><i>you’ve got a very big gap between what [PRIMARY SERVICE] offers and then what CAMHS offers, and it’s like, what about everyone else in between? And what [PRIMARY SERVICE] offer, my understanding is that it’s pretty much all CBT-focused, [...] there’s less kind of variety and less offer –Polly (Clinical Psychologist, FG3)</i></p> <p data-bbox="501 1339 1315 1525"><i>there’s a real gap I think, like we were saying earlier, a lot of the parenting stuff focuses on technique rather than what it’s like to be a parent, and certainly a parent of a child with autism, so I think it’s much needed. –Jan (Clinical Psychologist, FG3)</i></p> |
| Accessibility and Learning Needs | <p data-bbox="501 1543 1315 1682"><i>I think having options are going to encourage people to take part in this, more than just saying “this is how it’s delivered, that’s that”. –Rachel (parent, FG1)</i></p> <p data-bbox="501 1749 1315 1883"><i>I’m guessing probably a high percentage of parents of autistic children, one of the parents will be autistic or have additional needs as well –Jane (parent, FG1)</i></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |

| Theme | Additional Participant Quotes                                                                                                                                                                                                                                                                                                       |
|-------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|       | <p><i>I don't know if some autistic people struggle with the concept of imagery and that might be a bit of a barrier –Jane (parent, FG1)</i></p>                                                                                                                                                                                    |
|       | <p><i>someone who maybe have like theory of mind struggles might kind of struggle to follow the instructions –Claire (parent, FG2)</i></p>                                                                                                                                                                                          |
|       | <p><i>I also have a neurodiverse brain and that may be my perception of it, but my, um, I just look at those zig-zags and it's like, anger or fire or something like that –Rachel (parent, FG2)</i></p>                                                                                                                             |
|       | <p><i>I feel like that might not be helpful for perhaps like someone who's a black-and-white thinker –Claire (parent, FG2)</i></p>                                                                                                                                                                                                  |
|       | <p><i>Some people might struggle with things like building compassionate images that rely on things like tone of voice, and softening your facial expressions, you know when you think about the people's ability to read facial expressions and non-verbal cues –Shona (Clinical Psychologist, FG3)</i></p>                        |
|       | <p><i>I do think as guided self-help, it will work really well for more people –Jan (Clinical Psychologist, FG3)</i></p>                                                                                                                                                                                                            |
|       | <p><i>when you've got regular appointments with a clinician, you've got a certain level of feeling like you've got to show up, whereas if it's more kind of self-directed, when, whether people might start off quite keen but then life takes over and day to day pressures takes over –Polly (Clinical Psychologist, FG3)</i></p> |
|       | <p><i>choice is so important, so as Polly and Jan were saying, if there was a range of different exercises, some will land and some won't. –Shona (Clinical Psychologist, FG3)</i></p>                                                                                                                                              |

| Theme                       | Additional Participant Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Knowledge and Understanding | <p data-bbox="496 275 1316 421"><i>the automatic nervous system and the sympathetic nervous system, you know, and I'm like why do we need to know things like that really? –Rachel (parent, FG1)</i></p> <p data-bbox="496 479 1316 719"><i>you need to work out what you want to happen out of this, what is the reason for people doing this? Is it more about how the brain functions, or is it to learn skills about supporting themselves when times are difficult, what is this for? –Rachel (parent, FG1)</i></p> <p data-bbox="496 777 1316 972"><i>when I've been offered really general stuff like family support workers and stuff like that, I've felt quite aggrieved if I'm honest, because it's not felt specific to autism and it's just riled me –Jane (parent, FG1)</i></p> <p data-bbox="496 1030 1316 1225"><i>I wouldn't really be interested in the neurotypical side of it because it's just felt like when I've had generic support, it's just not felt relevant, so I think that would be a complete turn off for me –Jane (parent, FG1)</i></p> <p data-bbox="496 1283 1316 1576"><i>I really love the stuff where, you know when it goes really autism specific and it's like, you know, the critical self and what might come up and give real life examples, I've never seen anything like that, where, you know those kind of identities have been really shown in their way that would be experienced for our parents –Polly (Clinical Psychologist, FG3)</i></p> <p data-bbox="496 1635 1316 1830"><i>it's aimed at a very, very white middle class, educated group of people, and even though I suppose I happen to be one of them, I still wouldn't have gone to read this as it was too long – Rachel (parent, FG1)</i></p> |



| Theme               | Additional Participant Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|---------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                     | <p data-bbox="496 275 1327 421"><i>it's aimed at white middle class educated backgrounds and I think that if you think about the hard-to-reach communities, it isn't that</i> –Rachel (parent, FG1)</p> <p data-bbox="496 477 1327 667"><i>if it is something that parents are picking up themselves then I think it's quite a specific target audience of well-educated parents that it's going to appeal most to</i> –Jan (Clinical Psychologist, FG3)</p> <p data-bbox="496 723 1327 869"><i>I do wonder if you have to maybe have a certain level of education to access it, I don't know whether for some people it might be hard to access?</i> –Tara (Clinical Psychologist, FG3)</p>                                                                                                                                                                                                                                                                                                                                                                           |
| Psychological Needs | <p data-bbox="496 981 1327 1171"><i>some people can't actually tolerate that place of compassion for too long a time. Like, if they are in their threat systems already, it's quite hard to hold onto that compassion</i> –Shona (Clinical Psychologist, FG3)</p> <p data-bbox="496 1227 1327 1373"><i>people are quite often more blocked in their compassion towards themselves than they are in others</i> –Shona (Clinical Psychologist, FG3)</p> <p data-bbox="496 1429 1327 1574"><i>I definitely think our children should be taught about compassion, in schools because I think it's such a protective feature in everyone's lives</i> –Shona (Clinical Psychologist, FG3)</p> <p data-bbox="496 1630 1327 1776"><i>some of the words that they've used are very affirming as a parent, in that it's okay not to be the best parent in the world -</i><br/>Rachel (parent, FG2)</p> <p data-bbox="496 1832 1327 1937"><i>it does address some of the worries that you might have, um, and because you can see that they've taken that into account, I</i></p> |

| Theme | Additional Participant Quotes                                                                                                                                                                                                                                                                                                                                               |
|-------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|       | <p><i>feel that you'll feel more positive about keeping going –Rachel (parent, FG2)</i></p>                                                                                                                                                                                                                                                                                 |
|       | <p><i>if you think about just more generically about therapeutic models, one of the things that we always try and do first is to normalise it, and I think that the challenges we face as parents can be quite normalising and validating, and you sort of, “this is the problem, this is the solution”, you’ve got that buy in –Shona (Clinical Psychologist, FG3)</i></p> |
|       | <p><i>It’s not a sense of failing as a parent, it’s part of the course of trying to engage in something alongside all the trials and tribulations of parenting children, and parenting children that might have particular struggles day-to-day as well –Polly (Clinical Psychologist, FG3)</i></p>                                                                         |
|       | <p><i>there’s something in that, isn’t there, about kind of, relating to what are really common themes to parents so it feels like “yes” you’ve hit the spot even with the title, “they get me” even, you know, “from the outset”. –Polly (Clinical Psychologist, FG3)</i></p>                                                                                              |
|       | <p><i>I really think that unless you are a parent of an autistic child, you cannot comment on what you think their life is like. – Rachel (parent, FG1)</i></p>                                                                                                                                                                                                             |
|       | <p><i>Tone-wise when I was reading it, [...] it was more of a conversation, and [...] it was more like the person who wrote it actually understood that sometimes life doesn’t go as planned, and that’s okay, and it, the uh, tone was more reassuring, and it was less instructional. –Rachel (parent, FG2)</i></p>                                                       |
|       | <p><i>the compassion audio that I listened to was good, [...] because it helps me relax, because I was always on the go with my son –Mo (parent, FG1)</i></p>                                                                                                                                                                                                               |

| Theme | Additional Participant Quotes                                                                                                                                                                                                                                                                                                      |
|-------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|       | <p><i>I think the previous one was a bit like, we're telling you what to do because the theory says this is what you need to do, but this one is a bit more understanding as well I think [...] it's as if it's written by somebody who has some idea of what it's like to parent an autistic child. –Rachel (parent, FG2)</i></p> |
|       | <p><i>a compassion [...] based mindset is a universal thing, it's useful to everybody in any walk of life –Jane (parent, FG1)</i></p>                                                                                                                                                                                              |

*Note.* FG1 = Focus Group One; FG2 = Focus Group Two; FG3 = Focus Group Three; CFT = Compassion Focused Therapy; NHS = National Health Service; CAMHS = Child and Adolescent Mental Health Service; CBT = Cognitive Behavioural Therapy.

### 3.8 Full Feedback Received from the CFT Expert

*“This workbook is a wonderful resource for parents of autistic children. All the material and exercises are consistent with the theory and models that underpin Compassion Focused Therapy. There are many different ways to deliver CFT interventions and lots will depend on the target audience and their needs. Some interventions need to be long, whilst others can be brief, some need to be delivered by a therapist and others will find self-directed programs suit their needs. This parent workbook will be a valuable resource and will play a vital role in helping parents.*

*This CMT workbook is highly applicable and likely to be very helpful for parents of autistic children. Current research indicates how programs that help develop self-compassion are helpful for parents, autistic adults, and parents of autistic kids. I look forward to seeing the empirical results of the studies conducted using this program, which has been designed specifically for parents of autistic children.”*

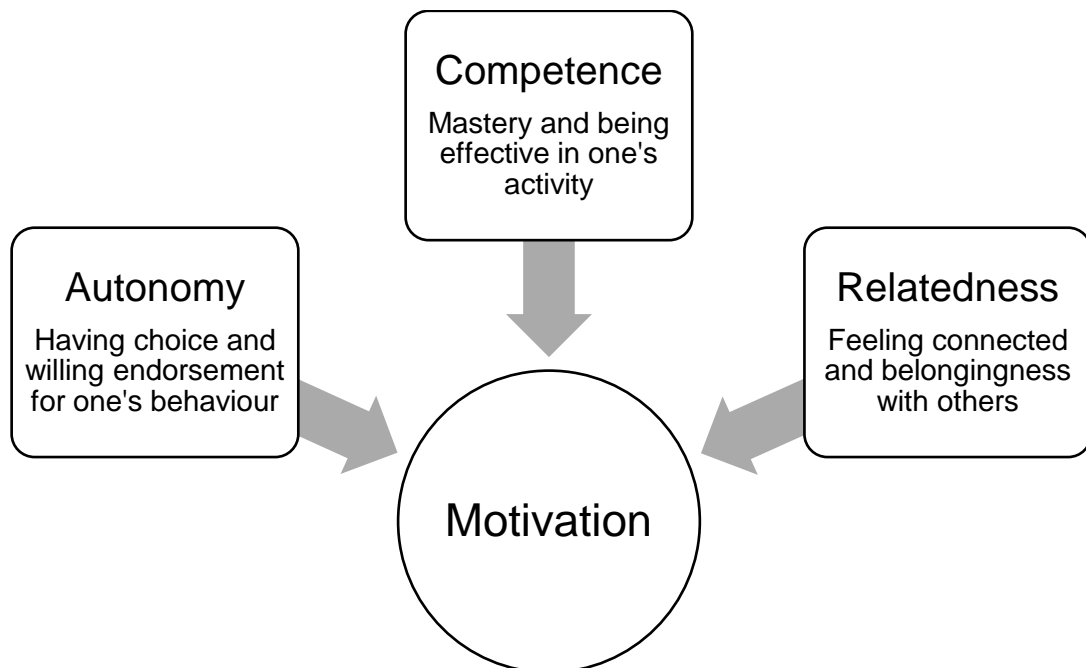
## 4.0 Extended Discussion

### 4.1 Defining Self-Determination Theory

Self-Determination Theory (SDT; Deci & Ryan, 1985) is described as a psychological macro-theory focussing on the effects of social-contextual factors to provide a broad framework explaining the intrinsic motivation process to influence human behaviour and personality (Deci & Ryan, 2012). It suggests that humans require three basic psychological needs to promote ongoing growth, integrity, and well-being: *competence*, *autonomy*, and *relatedness* (Ryan & Deci, 2022; see Figure 6). SDT postulates that greater need satisfaction contributes to more autonomous striving and optimal functioning, such as experiencing greater satisfaction regarding the three basic needs. Alternatively, reduced basic needs are the result of a more controlled reason for engagement, such as engagement due to feeling under pressure or guilty, which is believed to contribute towards compromised welfare (Duda & Appleton, 2016).

**Figure 6**

*Self-Determination Theory*



*(adapted from Deci & Ryan, 2022)*

SDT is understood as a meta-theory, evolving from laboratory and field research around the effects of extrinsic rewards and intrinsic motivation and developed by Deci and Ryan using six mini-theories. Intrinsic motivation is defined as doing something because it is interesting or enjoyable, whereas extrinsic motivation relates to doing something because it leads to a separate outcome, such as achieving an award, or avoiding punishment (Pelletier & Rocchi, 2023; Ryan & Deci, 2000).

**Cognitive Evaluation Theory.** This first mini-theory was developed to explain the effects of extrinsic factors on intrinsic motivation (Deci & Ryan, 1980, 1985a). It specified two key processes. Firstly, events leading to an internal perceived locus of causality, such as autonomy-supportive approaches, will enhance intrinsic motivation, whereas events resulting in an external perceived locus of causality, such as rewards, will reduce motivation. The second process involves the power of feedback events, where positive feedback within an autonomy-supporting context that supplements perceived competence is hypothesised to enhance intrinsic motivation, whereas negative feedback will likely reduce this. Finally, social-environmental factors are understood to have two relevant aspects to intrinsic motivation, where a controlling and pressured aspect may contribute to an external perceived locus of causality and reduce intrinsic motivation, and alternatively an informational aspect in the context of increasing competence and participant autonomy is understood to enhance intrinsic motivation (Deci & Ryan, 1980, 2012).

**Organismic Integration Theory.** This mini-theory addresses the concept of internalisation through differentiating between controlled versus autonomous internalised extrinsic motivation (Deci & Ryan, 1985a, 2012; Ryan et al., 1985). It defines distinct subtypes of extrinsic motivation that fall across a continuum of internalisation, including external regulation, introjection, identification, and integration. A person is hypothesised to be more motivated if their reasons for acting are more internalised and autonomous (Pelletier & Rocchi, 2023). The theory emphasises the importance of social contexts to support internalisation, such as relatedness and support for autonomy.

**Causality Orientations Theory.** This mini-theory is concerned with the interpersonal contexts that influence extrinsic motivational orientations (Deci & Ryan, 1985b, 2012). It defines three interpersonal contexts: autonomy-supportive, where people act according to their interest and value towards a situational context; controlling, where people become focused on rewards or approval; and impersonal or

amotivating, where people are orientated towards cues that signal indicators of incompetence, resulting in anxiety and demotivation.

**Basic Psychological Needs Theory.** This mini-theory was developed using the concept of universal psychological needs and to account for psychological health and wellbeing effects that are associated with greater autonomy, competence, and relatedness (Deci & Ryan, 2012; Ryan et al., 1985). The theory highlights that the three basic needs are crucial for good psychological wellbeing, and that when these are not fulfilled, there will be a hypothesised functional cost for the individual.

**Goal Contents Theory.** This mini-theory postulates that intrinsic versus extrinsic goals have a differing impact on motivation levels and wellbeing (Kasser & Ryan, 1996). Those holding more intrinsic goals, such as personal development or connection with a community, are more likely to experience greater motivation and wellbeing than those with extrinsic goals, related to subjects such as career or financial success.

**Relationships Motivation Theory.** This mini-theory posits relatedness as a critical psychological need in the context of relationships (Deci & Ryan, 2014). It suggests that autonomy-supportive relationships will satisfy the basic need for relatedness and facilitate a good quality relationship. Relationships with themes of control or contingent rewards are associated with low relatedness, and therefore result in poorer quality relationships.

#### **4.2 Application of Self-Determination Theory to Present Research Findings**

Several themes underpinning the key concepts detailed in the research findings could be viewed as directly applicable to the SDT macro-theory. Firstly, the difficult aspects of PACs' social contexts highlighted within the FA could be further considered using the causality orientations mini-theory (Deci & Ryan, 1985b, 2012). Particularly within focus group one, parents shared the multi-faceted potential barriers to engagement, relating to wanting a 'fix' for their situations whilst having limited time and energy due to managing parenting challenges and navigating bureaucratic systems within services. This could arguably indicate that attendees had tendencies to orient towards their environment and regulate behaviours using a controlling or non-self-determined form of motivation, where they appeared focused on extrinsic rewards, such as accessing a service or successfully alleviating their child/ren's distress. Linking

this with the goal contents mini-theory (Kasser & Ryan, 1996), this highlights how such extrinsic goals are more likely associated with lower wellness and greater psychological distress. This is an important finding and provides clinical and research implications around the need to understand the individual rationales of parents to seek a resource such as CMT-PAC in their current context, as their controlled orientation towards the intervention may reduce effectiveness outcomes. It will be important to promote the rationale for intrinsic goal setting with parents accessing this resource in the future, which may include the assessment and management of recipient expectations for the intervention.

The potential issue regarding parental fears around failure to complete the intervention as prescribed were raised across all focus groups, which may suggest that some future recipients are at risk of disengaging with CMT-PAC due to an anxious and possibly amotivated orientation. Literature documenting the effects of shame on the experience of motivation has assumed that shame reduces intrinsic motivation, as it is known to thwart the experiences of enjoyment and interest (Pekrun et al., 2002). Furthermore, performance-avoidance orientations have been linked to shame, where situations that engender incompetence may lower intrinsic motivation and increase extrinsic motivation, resulting in the possible extinction of behaviours, such as potential engagement with CMT-PAC (McLachlan et al., 2010). Contexts that may induce shame within individuals are hypothesised to contribute to the development of introjected regulation, and thus the motivation to avoid shame-inducing contexts (Deci & Ryan, 1985a; McLachlan et al., 2010; Ryan et al., 1985). This emphasises the importance of both de-shaming parent experiences, which is a core aim of CMT, but also to consider the possibility of intervention components inadvertently inducing parental shame. This was recognised across all focus groups, such as during parent focus group one, where parents expressed shame experiences relating to information around the developmental milestones for typically developing children. This finding provides clinical and research implications by supporting the rationale for the importance of stakeholder involvement to develop culturally-sensitive evidence-based interventions, as this enabled potential adverse effects to be identified and acted upon prior to intervention implementation.

Various facilitators that were raised included the promotion of fluctuating engagement, the use of a compassionate and validating intervention tone, and the support of diverse parent learning needs. These could be viewed as factors to increase

recipients' sense of autonomy and competence to engage with CMT-PAC. Intervention components which were perceived to foster a sense of feeling understood by another, including to experience social connection through guided support, and to experience an autism-specific intervention, could be considered using the cognitive evaluation, organismic integration, and relationships motivation mini-theories (Deci & Ryan, 1980, 2012, 2014; Ryan et al., 1985). These facilitators highlighted participants' preferences for an autonomy-supportive approach, which may promote a sense of relatedness and belongingness, as clearly emphasised to increase parent's anticipated motivation to use CMT-PAC during focus group two. Alongside providing further evidence around the applicability of SDT, this finding provides an important clinical implication around the importance of delivering interventions with PAC using an autonomy-supportive approach, to foster engagement and retention with the intervention.

### **4.3 Common Factors in Psychotherapy, and their Potential Application within Self-Help Materials**

Common factors are defined as therapeutic elements recognised across psychotherapies (Wampold, 2015a; Wampold & Budge, 2012) that may influence successful treatment outcomes, as initially identified by Rosenzweig (1936) and later popularised by Frank et al. (1993). Various common factor models exist, which are based on differing theoretical propositions, although conclusions related to the importance of common factors appear similar (Frank et al., 1993; Wampold, 2015a, 2015b; Wampold & Budge, 2012). The contextual model conveys a theoretical basis for common factors, suggesting three pathways whereby benefits are produced during psychotherapy using various mechanisms, rather than emphasising that specific therapeutic ingredients are required (Wampold, 2015a, 2015b). The pathways involve 1. The therapeutic relationship, 2. Co-creation of treatment expectations and understanding current distress, and 3. Enactment of health-promoting actions (Wampold, 2015a). The model incorporates a range of common factors, such as collaboration, goal consensus, empathy, alliance, positive regard, genuineness, expectations and cultural adaptations of evidence-based practice, alongside specific factors related to therapist competence, specific modality ingredients, and adherence to protocol (Wampold, 2015b). Meta-analyses have demonstrated that common factors have an important treatment effect (Horvath et al., 2011; Wampold, 2015a) although others have highlighted that the complex and multi-faceted nature of psychological



therapies means that whether they work successfully through common factors, specific factors, or both, remains not yet well understood (Cuijpers et al., 2019).

Amongst all proposed common factors, therapeutic alliance is often reported as the most important (Cuijpers et al., 2019). Bordin (1979) first defined therapeutic working alliance as a psychoanalytic concept composed of three core components: the bond between client and therapist, therapy goal consensus, and agreement regarding therapeutic tasks. A meta-analysis of over 200 reports and more than 14,000 treatments has evidenced a modest association between alliance and better treatment outcomes, although it is unclear whether authors of included studies operationalised the concept similarly (Horvath et al., 2011). Dimensions of therapeutic alliance are also evidenced to be significantly associated with dimensions of psychological well-being, leading to the therapeutic relationship been described as “*an important stabilizing condition of maturation and development*” (Prusiński, 2022, p. 12).

Participants in the present study raised requests that may reasonably be interpreted as supporting the development of a therapeutic relationship with CMT-PAC intervention components, including the self-help text. This raises questions regarding how or whether therapeutic alliance, alongside other common factors, can be experienced during psychotherapeutic interventions with little to no direct contact with a therapist, since there is evidence that good therapy outcomes can be obtained through these methods (Cuijpers et al., 2010; Moshe et al., 2021). Richardson and Richards (2006) suggest that overlooking common factors within self-help interventions may be a reason why previous self-help materials had reduced effectiveness, and advocated for the testing of self-help resources that incorporated both common and specific factors, although this body of literature has remained small. Peck (2010) shared hypotheses around self-help components being able to activate both specific and common factors by the way in which materials are written, and positioned therapists as a “*channel that activates the therapeutic factors*” (Peck, 2010, p. 151) similarly to written materials. However, Peck did not comment on how inherently interpersonal common factor components, such as therapist reflection around how they are perceiving their clients (Hubble et al., 1999) could be achieved in written format. Building on this, Richardson et al. (2010) reviewed three CBT-based self-help books for depression, including Gilbert's (2000a) *Overcoming Depression*, and provided a model of common factors in relation to self-help text, by using a phased approach for therapeutic relationship

development, as shown in Table 11. Further definitions for how each component are included within self-help texts are available within Richardson et al.'s (2010) paper.

**Table 11**

*Model of Common Factors Used Within Self-Help Books*

| <b>Phase of therapeutic relationship</b> | <b>Relevant common factors and objectives</b>                                                                                                                                                                                     |
|------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Establishing the relationship            | <i>Being accessible</i><br><i>Generating belief in recovery</i><br><i>Generating belief in helpfulness of the book</i><br><i>Empathy, warmth and genuineness</i><br><i>Negotiation of goals</i><br><i>Collaborative framework</i> |
| Developing the relationship              | <i>Guidance</i><br><i>Developing a secure base</i><br><i>Feedback</i><br><i>Responsiveness</i>                                                                                                                                    |
| Maintaining the relationship             | <i>Rupture prevention and repair</i><br><i>Flexibility</i>                                                                                                                                                                        |

*(adapted from Richardson et al., 2010)*

Interestingly, when applying this model to the present research findings, many suggested adaptations could be construed to support the therapeutic relationship. Adaptation requests during FG1 involved making the original resource more accessible, to share a clear rationale for the resource to generate belief in the helpfulness of the workbook, and to increase warmth and empathy, which could be understood as methods to establish the relationship between PAC and the workbook. Furthermore, flexibility was recognised throughout all stakeholder groups to support recipient retention during future feasibility testing, which may be viewed here as a method to maintain the therapeutic relationship. This finding appears to provide support for Richardson et al.'s (2010) model and furthers the evidence base through identifying that such common factors are specifically requested by PAC. Future feasibility testing of the resource will involve consideration regarding the intended and unintended

outcomes associated with CMT-PAC adaptations, and as such may provide insight into whether common factors interwoven in the text may influence intervention effectiveness.

#### **4.4 Fear of Compassion**

Compassion motivation can be feared, blocked, or resisted by individuals for several reasons (Gilbert & Mascaró, 2017). Fears may relate to feeling undeserving of compassion, or the possibility of emotional overwhelm whilst facing distress, and further blocks include feeling unsure how to be compassionate or experiencing highly critical or abusive backgrounds (Gilbert, 2019). Our capacities for compassion are theorised to be rooted within attachment systems (Gilbert, 2010; Gilbert et al., 2011), based on the work of Bowlby (1969, 1973, 1980). Gilbert et al. (2011) describes the attachment system as operating like a book, where it may close during adverse interpersonal experiences, such as trauma, abuse or neglect, but may re-open and reactivate emotional memories when compassionate capacities are stimulated through experiences with another or during CMT exercises. Punitive parenting practices, such as criticism and over-reaction, may lead to a classically conditioned response, where attachment figures who are associated with soothing experiences become paired with threat (Kirby, 2019; Kirby et al., 2019). Aversive emotional experiences are therefore associated with compassion, resulting in individuals learning to fear it. Shame is further understood to increase an individual's proneness to re-experiencing fear or avoidance whilst in receipt of compassion, as experiencing shame creates a sense of feeling under threat, due to being perceived as defective, therefore activating the threat affect regulation system (Matos, Duarte, & Pinto-Gouveia, 2017; Merritt & Purdon, 2020).

The FA identified several anticipated barriers to compassion, including fears about not being able to complete the exercises as instructed, evidence of self-criticism and self-blame, and the possibility that future recipients' backgrounds include interpersonal trauma, therefore could result in an aversive response to compassion cultivation during self-directed practice. As discussed, it is reasonable to interpret these concerns as resistance towards, or fears of compassion. Although theoretically, this makes sense when considering the significant levels of self-criticism, stigmatisation and poorer mental health outcomes experienced by this population (Bohadana et al., 2019; Sirois et al., 2019), fear of compassion is not yet identified within PAC literature. The influence of this factor is important to consider throughout planning and

undertaking compassion-based intervention testing with this population, as has been recommended by cross-sectional studies (Neff & Faso, 2015; Torbet et al., 2019). If not addressed, fear of compassion may result in active resistance towards engaging with compassionate exercises, which may limit the effectiveness of such interventions with little to no direct therapist involvement, and could contribute to increased attrition (Gilbert et al., 2011). At worst, fear of compassion could contribute to avoidable harm experienced by participants, should compassion-generating exercises elicit hyperactivation of aversive attachment-related experiences, when individuals may struggle to self-soothe during self-directed practice (Gilbert, 2014a; Mikulincer & Shaver, 2019).

This finding leads to important clinical implications around how fear of compassion is measured and addressed in future feasibility testing and beyond, as emphasised by CPs within FG3. A self-report measure, such as the *Fear of Compassion Scales* (Gilbert et al., 2011) may support screening procedures for future study participants. Importantly, as highlighted by CP participants, fear of compassion should not be viewed as an exclusion criterion for compassion-based interventions. Contrarily, interventions such as CFT can facilitate the development of intra- and interpersonal safeness, and working through an individual's resistance to compassion could provide an important therapeutic effect (Gilbert, 2010) as fear of compassion is also correlated with poorer mental health difficulties including self-criticism, depression, anxiety, and stress (Gilbert et al., 2012). This finding provides further justification for the addition of a guided support element during CMT-PAC delivery, as this may further provide opportunities for clinicians to assess and work through recipient resistance, and to dynamically assess risks relating to compassionate exercises triggering unforeseen distress.

#### **4.5 Adherence to Implementation Protocol versus Clinical Flexibility**

The translation of evidence-based psychological interventions to new population contexts has resulted in a major dilemma within implementation research around fidelity versus adaptation, where the two constructs are defined as opposed yet closely related elements (Pérez et al., 2015). Fidelity is understood as the degree to which an intervention is implemented as directed by research-based evidence and is typically understood as an implementation outcome that influences the intended effects of an intervention (Carroll et al., 2007; Pérez et al., 2015; Proctor et al., 2011).

Researchers have frequently attempted to measure fidelity, to provide evidence that the outcomes recognised during and after an implemented intervention were associated with the intervention program itself (Harn et al., 2013), to provide evidence for an 'empirically-supported treatment'. However, the evidence base involving such studies is limited by variability in both how fidelity is defined and assessed (McHugh et al., 2009).

Adaptation instead involves changes to an intervention by the facilitator or recipient (Kirk et al., 2020). Practitioners may inevitably adapt their working approach for a multitude of reasons, such as the belief that it will better fit the core components of an intervention, or to complement their own working style, or to meet the needs of the person they are working with (Johnson & McMaster, 2013). These reasons could be perceived as the phenomenon of therapist drift, defined as when clinicians stray from evidence-based practice (Speers et al., 2022; Waller, 2009). Originally recognised within CBT clinician research, therapist drift is believed to reduce treatment integrity (Waller & Turner, 2016). However, substantial health inequalities are identified within mental health care, highlighting that the interventions offered by services remain unreachable for under-served or 'hard-to-reach' communities, so there is a recognised need to make interventions accessible to people from diverse backgrounds (Arundell et al., 2021).

Considerations to preserve intervention fidelity whilst maintaining clinical flexibility often focus on practitioner adherence and competence (Dinger et al., 2015; Mazzucchelli & Sanders, 2010; Serfaty et al., 2020) whereas there is limited research exploring adherence and flexibility within self-help interventions, where more onus is placed on the recipient to adhere to a treatment protocol independently. Current recommendations include prompting methods, such as use of automated emails (Titov et al., 2013) and social support (Spence et al., 2019), which are hypothesised to be covered through implementation of guided support during the CMT-PAC future study. In terms of CMT-PAC being used in practice, there is a notable dilemma regarding treatment flexibility, should recipients wish to maintain a fluctuating engagement dynamic. From an efficacy research perspective, there will need to be further considerations regarding how intervention effectiveness and adherence to protocol is monitored, as fluctuations in practice is likely to impede upon the outcomes from testing. However, in a real-world clinical setting, it may be argued that the promotion of rigid adherence to PAC may lead to disengagement with the resource as this would

counter the autonomy-supportive approach that all stakeholders advocated for within the present study (Deci & Ryan, 1985a). This dilemma will require further consideration during development of an adherence protocol for future feasibility and efficacy studies of CMT-PAC, prior to a future large-scale RCT.

#### **4.6 Autism-friendly Adaptation Principles**

NICE (2021a) provide professional guidelines for the adaptation of mental health interventions, which were considered during all adaptation phases during the current research (see section 3.4 for further details). These adaptations are not felt to have a detrimental impact on the experience of CMT-PAC by non-autistic PAC. The guidelines outline that adaptations should include:

- *A more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and 'tool boxes').*
- *Placing greater emphasis on changing behaviour, rather than cognitions, and using the behaviour as the starting point for intervention.*
- *Making rules explicit and explaining their context.*
- *Using plain English and avoiding excessive use of metaphor, ambiguity and hypothetical situations.*
- *Involving a family member, partner, carer or professional (if the autistic person agrees) to support the implementation of an intervention.*
- *Maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible (such as using computers to present information).* (NICE, 2021a, s. 1.6.3)

#### **4.7 Small Scale Compassion-Based Intervention Studies with Autistic Adults**

##### **4.7.1 Aspect Self-compassion Program for Autistic Adults (ASPAA)**

The ASPAA (Cai et al., 2024; Edwards et al., 2024) is an Australian self-guided online program containing psychoeducation, self-compassion practices, and self-reflective exercises based on CFT (Gilbert, 2014b) and the Mindful Self-Compassion program (Neff & Germer, 2013). The experiential exercises included a grounding exercise focusing on the soles of their feet, finding a safe form of soothing touch,

progressive muscle relaxation, and loving-kindness meditation. ASPAA was reported to be co-produced by autistic and non-autistic researchers and an autistic advisory group, and brief detail around the adaptation of the program is provided by Cai et al. (2024).

A total 39 autistic adults completed the full program, with an attrition rate of 26%. Five of 39 participants completed the intervention a week later than planned due to personal reasons. Findings indicated statistical increases in self-compassion, and psychological wellbeing, and decreases in negative affect, anxiety and depressive symptoms, and emotion regulation difficulties, all with large effect sizes. Notably, 54% of the participants reported experiences of 'backdraft'; a term referring to initial distress or emotional turbulence when first attempting self-compassion practices (Cai et al., 2024; Germer, 2023). Practices most associated with backdraft were loving-kindness meditation and feeling the soles of your feet, where qualitative feedback indicated participant self-criticism and discomfort around focusing on the physical sensations. However, most participants were reported to have reduced experiences of backdraft through regular practice and shared beliefs that this could reduce with time. This finding mirrors the potential issues raised by stakeholders in the present study around autistic parents' differences regarding interoception and self-criticism. However, Cai et al. (2024) provide important tentative evidence that a self-guided program for autistic adults appeared efficacious and acceptable to their autistic participants, despite around half experiencing backdraft. The study authors provide recommendations around delivery of a guided component with a mental health clinician to safeguard from the consequences of backdraft, as will be used within CMT-PAC.

#### ***4.7.2 Compassion Focused Therapy: Single Case Pre-Experimental Study (SCED)***

An individual CFT intervention (Riebel et al., 2024) of twenty active sessions was facilitated with a 46-year-old autistic man residing in France. The intervention components are detailed by Riebel et al. (2024) and included soothing rhythm breathing, safe place imagery, compassionate self-imagery, ideal compassionate other imagery, and compassionate letter writing. The narrative intervention summary provided appears to indicate that the participant was able to engage appropriately with compassionate imagery tasks, which were supported through linking these with the participant's specialist interests, using visual prompts, and choosing of music pieces to accompany compassionate practices.

The intervention was interpreted to be acceptable and feasible for the participant, who missed no sessions and had completed a detailed diary throughout the SCED to evidence between session practice. Tau-U calculations indicated a very large increase in self-compassion through the intervention, complimented by lower daily shame scores. Self-stigma scores were variable at baseline and moderately decreased during the active treatment phase, although when comparing the baseline with the conceptualisation phase, there was no statistically significant change in self-stigma. It is acknowledged that the evidence base around using compassion-based interventions with autistic adults remains in such an early stage, and findings from this project are not generalisable to the population of neurodivergent adults. However, studies such as this provide initial evidence towards the potential appropriateness and accessibility of compassion-based interventions for autistic adults and can include valuable adaptation ideas to support neurodiverse adults to access and engage with such interventions in practice.

#### **4.8 Further Implications**

Further findings that were not explicitly recognised across all feedback phases are briefly discussed here, as these observations could provide further tentative clinical and research implications. Firstly, as detailed in the FA results section, one parent during FG1 shared that PAC who may not yet understand their child/ren's differences related to neurodivergence may find it difficult to apply the principles of compassion in the moment, or could find the approach unhelpful, as they are no closer to understanding their child's support needs. This finding highlights the importance of post-diagnostic support provision to PAC, including a need for better provision of person-centred psychoeducational content that is linked to their child's own abilities and support needs, to supplement PAC understanding. Although this is not the primary aim of an intervention like CMT-PAC, whether contextual factors contributing towards greater parental stress, such as this, may reduce effectiveness of compassion-based interventions for parents is a question for future research. However, it is recognised that future recipients could turn to an intervention such as this with similar contexts. Therefore, brief psychoeducational components relating to the common autistic traits in children were added to the resource. It is beyond the scope of the resource to provide post-diagnostic learning to PAC, but clinical implications associated with this finding include development of, and signposting to quality post-diagnostic support options and



clear documentation regarding the aims and scope of compassion-based interventions, such as CMT-PAC.

Secondly, PAC during FG1 described various negative emotional experiences whilst reading information that was perceived as too general or unrelated to parenting an autistic child. For example, one parent described feeling “aggrieved” when offered non-autism-specific interventions historically, and another described experiencing guilt whilst reading about the typical developmental milestones for children in the original resource, as this led to cognitions relating to their child ‘not being normal’. This finding highlights that clinicians must not assume that generic parenting interventions are directly applicable to all PAC, and identifies an increased potential risk of adverse effects, should clinicians not consider this carefully. This finding further justifies a need to adapt interventions for different client group contexts (Moore et al., 2021) and holds important clinical implications relating to the assessment of self-help materials to ensure that content appears relevant, applicable, and relatable to PAC or other target population groups, as advised by the World Health Organization (2024).

Finally, one PAC shared their concern that CMT-PAC may become used by services as a tokenistic intervention, to be offered instead of direct psychological support. Although this resulted in a brief statement within the intervention to highlight that it should not be used in this way, this finding raises further considerations regarding how the intervention is understood by PAC and service providers, and how this may be advertised in future. It is reasonable to interpret that clinicians in this situation are viewed by PAC as gatekeepers to accessing service support. Clinical implications therefore include ensuring that wellbeing interventions such as CMT-PAC are not labelled as an alternative to in-person service support. Clear conversations are required between PAC and clinicians, during times when clinicians are offering a preventative well-being intervention. Such approaches should be offered following a good quality assessment of PAC support needs, the formulation that self-help may be applicable, and should involve highlighting that the recommended intervention is something that may meet PAC support needs effectively.

#### **4.9 Detailed Limitations**

The collection of participant demographic information was provided for further context around the characteristics of those who were actively involved with shaping the

CMT-PAC resource. The total participant sample sizes were smaller than anticipated for the research, there was notable homogeneity in the demographic characteristics of the PAC and CP stakeholder groups. For example, all identified as female and despite active attempts to recruit fathers of autistic children to comment on study materials, this was not achieved, adding to the current underrepresentation of fathers within PAC research literature (Braunstein et al., 2013; Lashewicz et al., 2019). It is beyond the scope of the present study to provide evidence-based answers for why the apparent homogeneity of the sample had occurred, but practical barriers, such as lack of availability due to full-time work, are often cited as the most significant barrier for fathers to contribute to research (Parent et al., 2017; Yarmych & Persky, 2023). Furthermore, historic social norms regarding the gendered roles of parenting have often presumed that fathers are less involved with childrearing than mothers, to the extent that fathers have been viewed by some as non-primary caregivers (Cabrera et al., 2018). This assumption, whilst steadily becoming more challenged, has been further perpetuated by earlier attachment theory research that often focused on mother-child bonds, reinforcing the view that mothers are primary caregivers (Cassidy et al., 2013). Available demographic studies relating to UK-based Clinical Psychologists also highlight that an approximate 75.4% identify as female (Kanceljak & Calia, 2023; Health and Care Professions Council, 2020) which may account for the increased likelihood that recruited participants were also all female in the present study.

Although generalisability is not an aim of qualitative research such as this, it is still worth highlighting that PAC and CPs from differing backgrounds may have provided further novel or potentially contradicting adaptation suggestions to those that were received during data collection and so the results of the present study should not be viewed as generalisable. Furthermore, the chief intervention output from this study (CMT-PAC) should not be viewed as finalised, as this is hoped to undergo future feasibility testing, which may lead to further intervention refinement, alongside ongoing evaluation regarding the workbook's application across groups with different characteristics to those involved in the present research. Therefore, the results provided remain justified as relevant and useful, though should be viewed as a first of many steps required to understand the adaptations needed to use this resource with PAC. It is hoped that future research may further this evidence through testing and commentary with greater numbers of PAC and CPs.

Additionally, due to recruitment difficulties for PAC feedback phases, FG2 involved both new and returning participants to comment on the updated CMT-PAC, meaning that not all participants had seen the original resource, and the semi-structured interview schedule required alteration in-session to incorporate these differences. This was unforeseeable due to participant drop-out and is likely to have influenced the nature of suggested adaptations received in FG2. However, subjectively the broadened range of experiences did not appear to reduce the richness of the data collected and could be viewed as arguably a strength, by promoting discussion amongst participants. However, dominant voices were apparent in all focus group discussions, despite active attempts to encourage group discussion by the moderators, and it is possible that self-selection during recruitment procedures meant that participants with strong views expressed interest in taking part. This may have resulted in some views remaining unspoken within the focus groups, due to groupthink (Kitzinger, 1995). Further attempts were made to mitigate this through provision of opportunities to obtain further written feedback from participants in later phases, but none were received. The reason for the lack of feedback is not known, but it is reasonable to hypothesise that this could be due to practical factors such as the high parenting and/or occupational demands of participants that would prevent a further review of CMT-PAC, or the possibility that this was not completed by participants due to it being labelled as an optional request. Looking to the differences in responding styles within the focus groups (see section 3.4 for details), where participants appeared more vocal whilst providing negative feedback in comparison to positive feedback, it could be tentatively hypothesised that no feedback was provided as participants had no disagreements about the final version of CMT-PAC, but this cannot be confirmed as there is no information available to support this assumption.

Changes to the study design were made during phase two of data collection, through the addition of further stakeholder feedback phases (three to five), instead of immediate progression to feasibility testing. It is acknowledged that the linear phases of feedback retrieval and adaptations may have risked the possibility that adaptations at a later stage contradicted those requested by PAC in earlier phases. Active attempts were made to reduce the risk of this, through thorough documentation of all adaptations completed within the Microsoft Excel spreadsheet, and through sending the latest version of CMT-PAC to participants from all project phases who had opted to receive an updated copy, with an open invitation to share further written feedback, but none was received.

The first CFT practice manual is due for publication later this year (Petrocchi et al., 2024) and so was not available to guide adaptation processes during the present study. Instead, a range of CFT and CMT key texts (Gilbert, 2010; Gilbert & Procter, 2006; Irons & Beaumont, 2017; Irons & Heriot-Maitland, 2021; Tirsch & Gilbert, 2015) were referred to throughout adaptation. This slightly increased the risk of potential deviation from core mechanisms of CMT during refinement phases due to the possibility of variance within published approaches that were referred to, although attempts to uphold theoretical coherence were confirmed as effective by CFT-trained clinicians and an expert in the field.

Finally, in contrast to recommendations within the NMC/NIHR complex intervention development framework (Skivington et al., 2021a), the research team are unable to comment on the economic viability of the developed intervention at this stage. It is hoped that this can be assessed in later phases of implementation and evaluation.

#### **4.10 Directions for Future Research**

Several questions have been raised throughout the current research process, which could be considered during further adaptation, testing, and evaluation of CMT-PAC. The below questions are identified following discussion of research findings, or by participants during data collection.

- How feasible is CMT-PAC in practice with PAC?
- How effective is CMT-PAC in reducing stress in PAC?
- How effective is CMT-PAC in cultivating compassion in PAC?
- How effective is CMT-PAC in increasing life satisfaction in PAC?
- Does parent engagement with CMT-PAC influence the mental health and wellbeing outcomes of their child/ren?
- What scales may be appropriate to measure parent and child distress when facilitating CMT-PAC during future feasibility testing?
- How could a treatment protocol be developed to guide the CMT-PAC feasibility study when taking into consideration flexible adherence and intervention fidelity?
- How might adherence to protocol be measured when facilitating CMT-PAC?
- How effective is CMT-PAC in reducing parent distress when delivered as a guided self-help intervention, versus a self-help intervention?

- How effective is CMT-PAC in reducing parent distress when delivered as a waitlist intervention, versus a treatment-as-usual group?
- Is the CMT-PAC an economically viable preventative mental health intervention, in comparison to treatment-as-usual conditions for PAC?
- Who are best placed to deliver the guided support element of CMT-PAC?
- How effective is CMT-PAC delivered as a peer-led guided self-help intervention within parent groups, versus through guided support with a mental health clinician?
- What are the training needs of personnel facilitating the guided support element of CMT-PAC?
- What pre-requisite skills may be required by PAC before engagement with CMT-PAC?

## **5.0 Reflections**

I kept a reflexive diary throughout the research to document my ongoing thoughts and feelings throughout the process, to remain consciously aware of how these may influence my approach to the study. This helped me to maintain my pragmatic epistemological position, as it ensured that the research questions remained a core focus during my decision-making, particularly whilst I was faced with several challenges that led to significant changes to my study design. I attended regular supervision with research team members, who had clinical and research experience regarding the methodologies used and the target population group, which supported my ongoing reflective process. The below is a summary of my reflections over key stages of my research project, including the challenges that I had faced and how these were best resolved. Quotes from my reflexive diary and supervision logs are provided below.

### ***Researcher Stance***

It was important to consider what I personally brought to the project as the lead researcher, as this likely influenced my working approach. As stated in my application for clinical psychology training, I wanted to use skills developed through training to be part of the movement towards increasing access to preventative and evidence-based psychological well-being interventions. My own background involved supporting a neurodivergent family member to seek an autism assessment during their adolescence, which opened my eyes to the multiple barriers, long waiting times, and bureaucratic processes involved when accessing this through current NHS systems. The lack of quality post-diagnostic support at the end of this experience further highlighted to me the impact of this current service gap. I witnessed changes relating to the well-being of members within the family system as they worked through a process of adjustment to the autism label, whilst trying to navigate further services to access support.

During my master's study, I was privileged to undertake a student placement in child and adolescent mental health services, where I conducted a service evaluation to understand parent and carer's experiences regarding the services' autism assessment pathway. Participants shared similar stories involving hurdles to accessing an autism assessment, and described difficulties related to their own mental health throughout and beyond this process. Upon completion of this degree, I worked within adult

intellectual disability (ID) intensive support services as an assistant psychologist, where I experienced countless occasions where those with an autism diagnosis but no ID were declined support due to service eligibility criteria. There were many times where I felt that parents and carers could have benefited from separate and adapted support, which took their current parent context into account, as many felt unable to access therapy via general adult mental health services due to their caring arrangements and financial constraints. These professional experiences further fuelled my aspiration to be part of improving support options for autistic people and their families.

Finally, my second-year training placements were within two autism services, and I later discovered my own neurodivergence. In relation to this research project, I embraced these experiences as key strengths which have supported my understanding and implementation of reasonable adjustments to psychological therapies (including CMT-PAC) that may be required for neurodivergent people. I believe that my representation as a neurodivergent researcher within this project is a valuable addition. Nevertheless, all above factors described were discussed within research supervision, to ensure that key decision-making or interpretations arising from analyses were grounded in the research questions and data collected.

### ***Project Development***

I knew from commencement of my training that I wished to contribute to neurodevelopmental research. Initially, my interests were focused around adapting and streamlining psychological support for autistic adults, but it took time to filter down my ideas into a possible research question which would both meet the assessment criteria for the thesis project and be likely feasible to complete within the time constraints of the training programme.

*Reflexive log (November 2021): I want to make a difference to the lives of autistic people and their families, so I want to do an intervention study to further the evidence base around therapies with this population, but I keep hearing that my ideas are too big. Those that chose a project from the research handbook are already set-up, and I feel like I'm already behind!*

I eventually found myself re-reviewing the research handbook and became interested by the projects listed by Mark around parental self-compassion and children's behavioural difficulties amongst young people with autism/ID, particularly in

relation to projects focusing on experimentally increasing parental self-compassion, and measuring the impact on different mental health variables, such as guilt and shame. My theoretical knowledge of CFT was limited prior to starting on the course, but by engaging with the literature around compassion, I recognised the importance of seeing how this could support parental wellbeing.

However, when taking this to the research panel presentations, a key concern from staff was the lack of compassion-based intervention for PAC that was readily available. One staff member said that creating an intervention would already be an entire thesis project, and to my dismay I was given several 'amber' and 'red' ratings regarding proceeding with this project. Thankfully, through further reviews of the literature and by contacting CFT researchers to enquire about any current projects relating to parents, I was excited to hear from Dr James Kirby, who kindly provided the original resource as the basis for this study. This enabled me to complete and pass my research protocol for a two-phase project, which would have involved first adapting the resource in consultation with PAC through two focus groups, to then assess the acceptability, feasibility, and efficacy of the resource through pilot testing using a single case series design.

### ***Ethical Approval Process***

My research timeline incorporated time for ethical application on one occasion, prior to phase one of my original project (intervention adaptation) plus a short amount of time for further ethical amendment for the subsequent stage of pilot testing, as recommended by my research supervisors and senior research tutors. I quickly recognised that I had underestimated how long it would take to receive ethical approval from the university ethics committee. My pre-planned recruitment strategy for PAC focus groups involved recruiting from a research insight group that is organised by a well-known autism charity organisation. However, whilst my ethical application was under review, I discovered that the organisation had closed applications for research involvement. Following discussion with my supervisors, we agreed that I would send an ethical amendment to broaden my recruitment strategy to include social media, PAC support groups and charity organisations. During later correspondence with the ethics committee, I discovered that I would need to undergo a second full ethical review for the feasibility testing phase of the research, due to the amount of difference from the originally approved study details, which had contradicted my expectations:



*Supervision log (March 2023): Trainee concerns regarding delayed ethics application - senior research tutor has advised against second ethics application for testing phase of project.*

I shared this feedback amongst the research team and considered ways to adapt the research timeline to compensate for the second ethics application. I had begun to place pressure on myself to complete the adaptation stage of my research promptly, so that I could conduct the full project as outlined in my protocol.

### **Recruitment Issues**

Once advertising my study on social media, the research was likely targeted by fraudulent participants, which risked reducing the integrity of my research (O'Donnell et al., 2023; Sefcik et al., 2023; Woolfall, 2023). I brought this to my research supervisors' attention to seek advice on how to proceed and decided to offer screening calls to those expressing interest, as already described within my approved ethical application. I outlined that the purpose of screening would involve verification of participants' understanding of the project following our email correspondence, and to provide opportunity to ask questions, which served to support the informed consent-taking process and ensure that respondents met the eligibility criteria for the project. Most respondents subsequently agreed to meet via Microsoft Teams call, but then did not attend. I felt initially quite upset by this, as I offered a significant amount of screening appointments which had taken up several of my available study days, which could have been utilised for other course demands.

*Reflexive log (April 2023): Recruitment issues are having a significant impact on my study time, and I'm starting to feel overwhelmed. I'm managing so many screening DNAs and repetitive emails. I have other course assignments due too, and I'm struggling to juggle recruitment at the same time.*

From the few respondents who attended screening calls, I observed that many provided similar responses in terms of their own age, the age of their child and where they were calling from. All logged into the call with their cameras off (there was no requirement for cameras to be on or off for the study), provided vague and minimal responses throughout, and the audio quality was often poor. Following consultation with the research team about my concerns, we jointly agreed that these respondents would not be eligible to participate, for reasons documented within section 2.2.2. This

was an important learning experience for me and highlighted the importance of planning for robust screening measures for online research, to reduce the risk of fraudulent participation, which I had not anticipated during study design or ethical application. I shared my learning with senior research tutors, in hope that this will be used to educate and prepare incoming DClinPsy candidates to be aware about an apparently growing issue of fraudulent research participants. I subsequently altered my recruitment strategy to focus on smaller local parent support groups online and in-person, and I recruited for my focus groups after significant delay.

The night before facilitating FG1, one PAC participant exercised their right to withdraw from the study. On the day, another participant attempted to attend, but did not unmute themselves or turn on their camera, then left the meeting minutes later, which left only three attendees. In the moment, I experienced a dilemma around facilitating or postponing the session, as I knew that we were below the recommended number of focus group attendees for research purposes (Kitzinger, 1995; Krueger & Casey, 2015; Stewart & Shamdasani, 2015), but I was aware that the participants who were present had already spent time reviewing the original resource and had made time to attend the call. This awareness led me to make the decision to continue the session as it felt more ethical than cancelling the meeting, and I am glad to have done so, as it was an insightful and fruitful discussion. However, this meant that I needed to go back out to re-recruit for FG2 to increase my PAC sample size, which contributed to further delays in progress.

### ***Changing Study Design***

At this stage, I had markedly deviated from my research timeline due to the above challenges. Furthermore, the feedback from FG1 signalled that the original resource required significant work before it could be deemed appropriate for progression to feasibility testing. I began to panic, as the second stage of my project no longer appeared feasible. I re-read guidelines for complex healthcare intervention development and considered the value of extending and enhancing the adaptation phase of the project. I began to plan methods to use consultation with a series of stakeholder groups, including parents, CFT clinicians and CPs working in services supporting PAC. I brought my above concerns and alternative ideas to the research team and was relieved when my plans were welcomed.

*Supervision log (May 2023): Plan to submit ethics amendment for further focus groups and continue recruitment via social media/support groups. Consideration of how we ensure theoretical coherence/completion of quality assessment for finalised workbook.*

*Possibility of expert review?*

During the re-design of my research, I attended a research clinic to gain insight on my plans from other research tutors, who queried whether I should move to conducting a series of individual interviews with PAC alongside focus groups and advised me to follow the Delphi method, rather than the current qualitative approach. I found this unhelpful, as I was trying to finalise a research methodology to undergo ethical amendment, and as I was shortly entering my final year of doctoral training, I felt I had limited time to consider alternative ideas. I brought the ideas around the Delphi method to the attention of my research supervisors, but ultimately, I chose to continue with my initial plan to use focus groups, with justifications outlined in section 2.5. We considered ways to structure and utilise the feedback from each focus group in a predetermined way, as is a strength of using the Delphi method.

### ***Data Analysis and Write Up***

Throughout the analysis, I made reflexive diary entries to document any reflections throughout my coding processes, which I then took to discuss with my research supervisors on an ongoing basis. I feel this supported greater transparency during the analytic process, particularly during more interpretive elements during the FA. I also documented my own responses to participants' contributions, which I took to research supervision to discuss further and consider how this influenced my approach towards the data. For example, after FG1 I noted how I felt taken aback after Rachel advised that the project should only be conducted by a PAC, as I did not meet this criterion. I used supervision to share my discomfort from this experience, and I shared my reflections around what might have influenced this request. I thought about participants' desires to have their contexts understood by developers, to influence how the CMT-PAC is adapted, which reinforced my motivation to use a stakeholder-informed approach to developing the intervention materials.

After conducting the DCA and looking back at the list of adaptations retrieved, I began to wonder how I would meaningfully report on this stage of analysis so that the adaptation process was clearly documented, as is recommended practice (O'Cathain

et al., 2019; Wight et al., 2016). I wanted to find a method to meaningfully categorise what adaptations were facilitated and why.

*Reflexive log (February 2024): Just using FRAME codes for goals for adaptation might seem a little unclear to readers... I need to read some more around best methods to report adaptation phases in my write up.*

In response, I returned to the literature to investigate further methods to report adaptation and came across recent papers that had used a variety of techniques to support the reporting process (Ametaj et al., 2021; Holtrop et al., 2022). This supported my decision to use the FRAME table (Table 1), but also made me think critically about what I wanted to convey in the report and how I could make these results useful to refer to during future intervention development stages. After all, I had already used the MADi to consider the impact of each adaptation on future intervention outcomes, so why not report adaptations in a way to supplement direct comparison to outcomes when the resource is eventually tested? Holtrop et al. (2022) documented various ways to categorise adaptations, and upon review, I felt it was beneficial to add the additional taxonomic analysis table to my reporting, as this provided a way to better summarise adaptation types per feedback.

In terms of the FA, Spencer et al.'s (2014) textbook greatly supported my understanding of this analytic approach and I referred to this a lot throughout my own analysis. However, I found myself spending a lot of time moving back and forth between indexing and re-constructing the initial coding matrix, as I didn't feel that the matrix was accurately capturing all potential topics of interest arising from the data. I had also read Goldsmith's (2021) FA process, which similarly involved data from three focus groups. I noticed that I began to compare my progress to their reported experience, as they had been able to move through FA stages with little need for amendment. Unhelpfully, I wondered whether this meant that I was doing a 'bad job' at data analysis.

*Reflexive log (March 2024): Coded data about acceptability seems to overlap with parent's attitudes about the intervention, their context, and the perceived usefulness of the resource... maybe I need to come at this from another way round? I feel like I've spent so much time coding and re-coding data, and I'm not getting any further forward, as everything feels like it interrelates... how am I supposed to pragmatically categorise themes that all link together?*

I chose to pause my analysis and reviewed the literature to read other qualitative researchers' experiences with FA. Reading Parkinson et al.'s (2016) paper helped me recognise that I was over-complicating the data management process, as I was attempting to identify concepts at this early stage as would happen during the data interpretation phase, rather than simply trying to categorise data to make this more manageable prior to charting and analysis. I looked back through the various versions of indexing that were saved on NVIVO14 and recognised that my latest attempt had successfully categorised all data that may answer the research question. This helped me to feel confident to progress to the charting stage, moving my analysis forward.

Once my results were finalised, I then wondered about how best to report the two analyses. I faced a dilemma around whether to include one in my journal paper and the other in the extended paper, or whether to include both in the journal paper. I brought this to research supervision and was advised that I could write two journal papers, but due to the limited time remaining before the delayed thesis submission date, this did not appear feasible to me. I spent further time planning what I needed to include in my journal paper and reading similar published intervention development studies, which supported my own planning for the structure of my paper. I was relieved to hear that research supervisors felt my results structure worked well despite including both analyses, when I received feedback on my drafted journal paper.

*Reflexive log (April 2024): Focusing on the FA results will more likely meet the marking criteria for my thesis than just the DCA, but I can't report the FA without sharing the context of how recommendations arose, as each were from a different stage of feedback about a different version of CMT-PAC. Thomas suggested that I write two separate journal papers (content analysis, and framework analysis) but I'm running out of time and I'm not convinced that I can't make this work as one paper.*

### ***Final Reflections and Implications for Future Practice***

Considering my project held a CFT focus, the irony is not lost on me that the series of challenges faced during my project often moved me into my own threat system at various phases of the research. As challenging as it has been, I now feel that I have space to appreciate the learning opportunities that this project provided me. I believe my research skills and knowledge have developed significantly, and I now feel confident to conduct and critically evaluate research with integrity. I think that my

learning throughout navigation of stakeholder-involvement and intervention adaptation will positively impact my future clinical practice, as I'm keen to advocate for more stakeholder involvement during service delivery projects. I'm hopeful that my learning around adapting psychological therapies for clients (particularly neurodivergent populations) will further improve my clinical practice and therapy outcomes, especially as I will be working post-qualification in a service where a higher prevalence of neurodiversity is recognised. Finally, this project enabled me to reflect on my own usual patterns of responses towards challenges and has taught me the value of taking a step back, observing my threat system has activated, and modelling self-compassionate processes as described within CMT. This has taken practice but has been a positive experience. I will be taking my own 'compassionate self' with me post-qualification!

I feel genuinely proud of what I have accomplished during this project, and I feel privileged to have created something that is anticipated to be meaningful, with support from all participants, the CFT expert, and the research team. Although I was not able to proceed to feasibility testing during my own project timescale, I can now see how valuable it was to extend the adaptation phase and seek further stakeholder feedback, as I believe this has improved the intervention further, and has identified more factors that may influence future testing, for prospective consideration. I remain deeply passionate about this project, and I look forward to my ongoing involvement in future stages of testing CMT-PAC when I am post-qualification.

**Journal paper: 7998**

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## Appendices

## **Appendix A**

### **Journal Submission Guidelines**

Psychology and Psychotherapy: Theory, Research and Practice

<https://bpspsychub.onlinelibrary.wiley.com/hub/journal/20448341/homepage/forauthors.html>

## Appendix B

### Written Permission to Adapt Original Resource

---

**From:** James Kirby <j.kirby@psy.uq.edu.au>  
**Sent:** 11 February 2022 06:53  
**To:** Mark Hudson (staff) <mzmh6@exmail.nottingham.ac.uk>  
**Subject:** Re: Compassion focused parenting

Hi Mark,

Yes all that sounds great to me. Good luck with it all

Here is the manuscript, which is under review at the moment. Likely will be rejected from this journal as it is a very good one

Please keep in confidence at this stage as it is still under review

Best wishes,  
james

---

**From:** Mark Hudson <Mark.Hudson@nottingham.ac.uk>  
**Date:** Thursday, 10 February 2022 at 9:23 pm  
**To:** James Kirby <j.kirby@psy.uq.edu.au>  
**Subject:** Re: Compassion focused parenting

Hi James,

Thanks so much for your response and for sharing your resources. It's always a source of joy when these opportunities for collaboration come up. I'm working with Prof. Thomas Schroder on this project, who has worked with Paul Gilbert at the CMF, so hopefully it should be really fruitful.

It looks like you've made some good progress in getting the research agenda started in this area. I was wondering, would it be possible to adapt the workbook you shared at all for a population of parents supporting a child with ASD? It looks really nicely written and well-structured, but it may be helpful to add some info about particular challenges of parenting in this population. I would of course acknowledge your role in the development of the materials and also reference your work in any future publications, and would be happy to share the resources with you.

Also, I didn't know if it would be possible for you to share preliminary findings or an abstract from the study about the parenting seminar? It may just help to evidence the materials in putting forward a research proposal.

Kind regards,

Mark

**Appendix C**  
**Ethical Approval Letter**



**DPAP Committee: 17/02/2023**  
**Supervisor: Dr Mark Hudson**  
**Applicant: Miss Francesca Kemp**

**Project ID: 3003**

**Project Title: Developing a compassion-based intervention for parents of autistic children**

Dear Francesca

The committee is pleased to confirm that the above study now has approval on the basis of your application and any subsequent clarifications. You must conduct your research as described in your application, adhere to all conditions under which the ethical approval is granted, and use only materials and documentation specified in your application.

If you need to make any changes (for example to extend your data collection timeframe, change the mode of data collection, or the measures being used), you must create and submit an Amendment Form. To do this, select the 'Create Sub Form' option from the Actions Menu on the left-hand side of the page in the online system and then select 'Amendment Form'.

With best wishes

A handwritten signature in black ink, appearing to read "Jen Yates".

Dr Jen Yates  
Chair of the DPAP Ethics Subcommittee

## Appendix D

### Ethical Amendment Letter



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DPAP Committee

28/06/2023

Supervisor:

Applicant : Francesca Kemp

Project: Project Id Developing a compassion-based intervention for parents of autistic children

The committee is pleased to confirm that the amendment relating to ref: DPAP - 2023 - 3003 - 1 has received approval. Please conduct your study following the amended procedures. If you need to make any further changes, please create a new amendment form.

yours sincerely

A handwritten signature in black ink, appearing to read 'Jen Yates'.

Dr Jen Yates

Chair of DoPAP Ethics Subcommittee



## Appendix E

### Ethical Amendment Letter



DPAP Committee

10/10/2023

Supervisor:

Applicant : Francesca Kemp

Project: Project Id Developing a compassion-based intervention for parents of autistic children

The committee is pleased to confirm that the amendment relating to ref: DPAP - 2023 - 3003 - 1 has received approval. Please conduct your study following the amended procedures. If you need to make any further changes, please create a new amendment form.

yours sincerely

A handwritten signature in black ink, appearing to read "Jen Yates", written in a cursive style.

Dr Jen Yates

Chair of DoPAP Ethics Subcommittee

## Appendix F

### Participant Information Sheet for Parents



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**School of Medicine**  
University of Nottingham  
Medical School  
Nottingham  
NG7 2UH

## PARTICIPANT INFORMATION

### STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

**Project Title:** Developing a compassion-based intervention for parents of autistic children

Student: Francesca Kemp (Francesca.Kemp@nottingham.ac.uk)  
Chief Investigator: Dr Mark Hudson (Mark.Hudson@nottingham.ac.uk)  
Secondary Supervisor: Prof. Thomas Schröder (Professor of Clinical Psychology and Psychological Therapies)  
Field Supervisor: Dr Corinne Gale (Clinical Psychologist)  
Ethics Reference Number: 3003

We would like to invite you to take part in a research study about developing a compassion-based psychological intervention for parents of autistic children. Before you begin, we would like you to understand why the research is being done and what it involves for you.

#### What is the purpose of this study?

Parents of autistic children can experience additional parenting demands and unique challenges. Research has shown that these parents are also more likely to experience difficulties themselves, such as stress, anxiety, low mood, lower quality of life and health-related problems when compared to parents of 'typically developing' children. Self-compassion has been shown to help with these difficulties, but more research is needed to see if it can help parents of autistic children.

This study aims to gather participant's feedback to support development of a new guided self-help intervention for parents of Autistic children. We hope to later trial the developed intervention and estimate that this could help to improve parents' self-compassion and reduce their stress. The intervention will be based on Compassion-Focused Therapy (CFT), which is designed to help people who experience problems like shame and self-criticism. This study is being carried out for educational purposes by a student on the Doctorate in Clinical Psychology and the findings will be written up as part of a dissertation.

#### Why have I been invited?

You have been invited because you responded to an involvement opportunity advert that was circulated through social media, autism support groups and charity organisations. We have invited people aged 18+ who are parenting a child aged under 18 who has a diagnosis of autism spectrum disorder. We believe that parents will be able to provide a valuable insight into how helpful and practically accessible the intervention is for other parents of autistic children. Participants can also take part if they are able to read and communicate using

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English and have access to the internet, video calling software (Microsoft Teams) and an email address. We are inviting five participants like you to take part.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign and return a consent form to the student leading the research project via the above email address.

You may change your mind about being involved at any time or decline to discuss a particular question. You are free to withdraw at any point before or during the study without giving a reason. You can do this by contacting the student using their email address above. If you withdraw during the study, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records. Existing information may have already been used in some analyses and may still be used in the final study analyses. Once you have taken part in a focus group, it will no longer be technically possible to withdraw your data.

#### **What will I be asked to do?**

If you choose to take part after reading this information sheet and the focus group guidelines, please fill in the consent form. Your email address will be held for the purposes of communication before and during the focus groups, but this will not be passed on to any third parties.

Once you have agreed to take part, a copy of the existing intervention will be emailed to you, alongside a list of topic areas and initial questions about the intervention from the lead researcher for you to consider. The focus of questions will be about how appropriate the intervention materials are for parents of autistic children. We will also send a weblink to a Demographic Information Form for you to complete. This will ask for information about your age, gender, ethnicity, marital status, age of your child and their diagnosis. This information will be used to inform the study report. You will be allocated a participant number at the top of the document to anonymise your responses. We will also send you full details of when and how the focus group will take place. If you have any concerns about what to do, please just ask.

You will then be invited to attend a remote focus group with other parents to discuss these questions together. The meeting would last for up to 90 minutes and will be held via Microsoft Teams. You can choose whether you would like your camera to be turned on or off. This meeting will be recorded using an encrypted Dictaphone, to be saved onto a password-protected secure server at the University of Nottingham. The meeting audio will be fully transcribed, to support the research team in analysing and acting upon group feedback.

The researcher will continue to develop the intervention and will later email an updated version to you. You will be invited to attend a second focus group held with the same guidelines as above. The purpose of the second group will be to comment on the updated intervention. Following this, the intervention materials will be finalised by the research team, and you will be thanked for your involvement.

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We will thank you for completing the research and re-provide our contact details should you wish to get in touch with the research team. Your feedback about the intervention will be taken into consideration and reported on. The results of the intervention development phase will be written up and your information will be fully anonymised. If you would like to know more about the results of the study, we will ask for your consent to hold your contact details so we can forward this information to you.

#### **Expenses and payments**

In recognition of the time and effort required, we would like to offer a voucher of £10 for your attendance at each focus group as a token of our appreciation (maximum of £20). If you are in receipt of state benefits, we advise that you discuss this with the researcher and get further information from Job Centre Plus before committing to taking part in the study. Meetings with the researcher will take place via video call using Microsoft Teams, which is free to download online. This aims to reduce the possibility of other expenses such as travel and parking. However, participants would need an internet connection to be able to join the meeting.

#### **What are the possible benefits of taking part?**

There is no direct benefit to you from taking part, but we hope that you find the focus groups to be a positive experience. The information we get from this study may contribute to the development of an intervention for parents of autistic children like yourself, which we hope may support the development of parental compassion and a reduction in mental health difficulties. It is envisaged that this intervention will later be trialled with a small number of people in future research to test initial effectiveness and feasibility of the intervention.

#### **What are the possible disadvantages and risks of taking part?**

We don't expect there to be any disadvantages to taking part. There are few risks involved in focus group research. However, one possible risk is of participants disclosing personal information or what has been said in the focus group once the study is over. In order to reduce any potential risks, the researchers will remind participants to respect each other's privacy and not repeat anything that has been discussed both in the consent form and verbally before the start of the study.

During the focus groups, you would not be asked by the researcher to provide any details regarding your personal experiences. However, you are welcome to use self-disclosure if you feel that this is manageable and appropriate to intervention development. A possible disadvantage of this is that for some people, discussing their own lived experiences of parenting an autistic child/ren might make them more aware of any pre-existing psychological distress. The researchers will not be able to provide psychological support to participants in this study but details of appropriate support services are available at the end of the information sheet.

As the focus groups will be facilitated online, there may be risk of fatigue from looking at the computer screen for an extended period of time. To mitigate this, the facilitator will offer breaks and remind you to look away from the screen if your eyes are getting tired.

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**Will my taking part in the study be kept confidential?**

To ensure confidentiality, only the research team will have access to the demographic information, audio recordings and transcribed focus group data. The audio recordings will be transcribed verbatim by the student. All personal details that might identify any participants will be removed upon transcription. The transcripts will be uploaded into a password-protected database and once the analysis of the transcribed interviews is complete, the audio recordings will be destroyed. Participants will be identified by a participant number only. We would like to be able to quote what you say in reports or publications. We will make sure that your anonymity is protected, but if you do not wish us to quote you, please tell us.

The information that you provide will be used to write a dissertation for the fulfilment of the Doctorate in Clinical Psychology and may also be used to write academic papers to be published in peer-reviewed journals and in presentations at conferences. If you would like a summary of the results, please email the supervisor Dr Mark Hudson (Mark.Hudson@nottingham.ac.uk) for a copy.

We will follow ethical and legal practice and all information will be handled in confidence. Under UK Data Protection laws, the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information and to read our privacy notice at: <https://www.nottingham.ac.uk/utilities/privacy.aspx>

We would like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. At the end of the project, all raw data will be kept securely by the University under the terms of its data protection policy after which it will be disposed of securely. The data will not be kept elsewhere.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the email addresses above.

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#### **Who is organising and funding the research?**

This research is sponsored by the University of Nottingham and is being funded by Health Education England (HEE).

#### **Who has reviewed the research?**

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Nottingham Division of Psychology and Applied Psychiatry Research Ethics Committee.

#### **What if there is a problem?**

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee [rita.gohil@nottingham.ac.uk](mailto:rita.gohil@nottingham.ac.uk) who will pass your query to the Chair of the Committee.

If you remain unhappy and wish to complain formally, you should then contact the Faculty of Medical and Health Sciences Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: [FMHS-ResearchEthics@nottingham.ac.uk](mailto:FMHS-ResearchEthics@nottingham.ac.uk)

We believe there are no known risks associated with this research study; however, as with any online activity the risk of a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous.

#### **Sources of Support**

##### Support programs for parents

To find your local licensed support team, please check the National Autistic Society online directory:

<https://www.autism.org.uk/what-we-do/support-in-the-community/family-support/earlybird-teams>

##### Charity Organisations

There are many local, regional and national charities about Autism in the UK. These can include lots of useful resources, online forums and telephone support lines. Here are a couple to get you started:

National Autistic Society: <https://www.autism.org.uk/>

Ambitious about Autism: <https://www.ambitiousaboutautism.org.uk/>

##### Other useful links (not autism specific)

Young Minds support for parents: <https://www.youngminds.org.uk/parent/>

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Mind: <https://www.mind.org.uk/>

NSPCC support for parents with mental health difficulties: <https://www.nspcc.org.uk/keeping-children-safe/support-for-parents/mental-health-parenting/>

Mental health services:

NHS help for families of autistic people: <https://www.nhs.uk/conditions/autism/autism-and-everyday-life/help-for-families/>

You could contact your local GP.

You could find a local NHS urgent mental health helpline (England only):

<https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>

Samaritans: <https://www.samaritans.org/> tel: 116 123

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## Appendix G

### Participant Information Sheet for Clinical Psychologists



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University of Nottingham  
Medical School  
Nottingham  
NG7 2UH

## PARTICIPANT INFORMATION

### STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

**Project Title:** Developing a compassion-based intervention for parents of autistic children

Student: Francesca Kemp (Francesca.Kemp@nottingham.ac.uk)  
Chief Investigator: Dr Mark Hudson (Mark.Hudson@nottingham.ac.uk)  
Secondary Supervisor: Prof. Thomas Schröder (Professor of Clinical Psychology and Psychological Therapies)  
Field Supervisor: Dr Corinne Gale (Clinical Psychologist)  
Ethics Reference Number: 3003

We would like to invite you to take part in a research study about developing a compassion-based psychological intervention for parents of autistic children. Before you begin, we would like you to understand why the research is being done and what it involves for you.

#### What is the purpose of this study?

Parents of autistic children can experience additional parenting demands and unique challenges. Research has shown that these parents are also more likely to experience difficulties themselves, such as stress, anxiety, low mood, lower quality of life and health-related problems when compared to parents of 'typically developing' children. Self-compassion has been shown to help with these difficulties, but more research is needed to see if it can help parents of autistic children.

This study aims to gather participant's feedback to support development of a new guided self-help intervention for parents of autistic children. We hope to later trial the developed intervention and estimate that this could help to improve parents' self-compassion and reduce their stress. The intervention will be based on Compassion Focused Therapy (CFT), which is designed to help people who experience problems like shame and self-criticism. This study is being carried out for educational purposes by a student on the Doctorate in Clinical Psychology and the findings will be written up as part of a dissertation.

#### Why have I been invited?

You have been invited because you are a Clinical Psychologist in the United Kingdom who has experience of working with parents of children with Autism Spectrum Disorder and have replied to our advert through professional networking. We are inviting 4-8 participants like you to take part.

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### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign and return a consent form to the student leading the research project via the above email address.

You may change your mind about being involved at any time or decline to discuss a particular question. You are free to withdraw at any point before or during the study without giving a reason. You can do this by contacting the student using their email address above. If you withdraw during the study, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records. Existing information may have already been used in some analyses and may still be used in the final study analyses. Once you have taken part in a focus group, it will no longer be technically possible to withdraw your data.

### **What will I be asked to do?**

You will be asked to electronically sign a consent form and complete a demographics questionnaire via email.

1. You will be sent, via email, compassionate mind training materials which have been adapted for parents of autistic children and recommendations which have been developed, regarding the delivery of this as a guided self-help intervention. These have been developed by the researchers and the therapy materials have also been reviewed by a service user group.
2. You will be asked to provide written feedback on the accessibility of these materials and recommendations for delivering compassionate mind training via guided self-help for parents of autistic children and suggest possible amendments you believe would improve the adaptations. You can structure your feedback in a way to suit you and there is no predetermined form; you may decide to write specific feedback throughout the documents, or you may prefer to write general feedback. You will be asked to provide your feedback within four weeks of receiving these documents and a reminder email may be sent if a response has not been received within three weeks. We anticipate that it will take you between 1-2 hours to review and provide feedback on the materials and recommendations for delivery of compassionate mind training as a guided self-help intervention.
3. The researchers will subsequently integrate the suggested amendments into the documents and return these to participants to read prior to being invited to a focus group, which will be at least one week later. The suggested amendments will be clearly marked throughout the documents; however, the origin of these suggestions will not be disclosed, unless participants choose to identify their suggestions during the focus group.
4. The focus group will be held online over Microsoft Teams at a time convenient for all participants and will be recorded using an encrypted Dictaphone. The researcher facilitating the group will share their screen and read through each suggested amendment, facilitating a discussion around the amendment and asking for a majority decision on whether the

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amendment should be incorporated. If a majority decision cannot be reached, the researchers will aim to incorporate both views into the documents.

5. Following this, a discussion will be facilitated during the focus group around adapting compassionate mind training interventions for parents of autistic children, the appropriateness of this approach and foreseeable advantages and disadvantages of using this approach. It is anticipated that this focus group will last no longer than 2 hours in total.

#### **What are the possible benefits of taking part?**

There is no direct benefit to you from taking part, but we hope that you find the focus group to be a positive experience. The information we get from this study may contribute to the development of an intervention for parents of autistic children, which we hope may support the development of parental compassion and a reduction in mental health difficulties. It is envisaged that this intervention will later be trialled with a small number of people in future research to test initial effectiveness and feasibility of the intervention. Your participation therefore has the potential to positively impact on service users by determining whether compassionate mind training via guided self-help would be a useful intervention, and what adaptations would be appropriate.

#### **What are the possible disadvantages and risks of taking part?**

Taking part in this research will take up approximately 4 hours of your time, however, this is dependent on how long it takes you to review the documents sent prior to the focus group. It is highly unlikely that you will experience any distress during the focus groups, as you will be asked to speak about your professional skills and experience.

As the focus groups will be facilitated online, there may be risk of fatigue from looking at the computer screen for an extended period of time. To mitigate this, the facilitator will offer breaks and remind you to look away from the screen if your eyes are getting tired.

#### **Will my taking part in the study be kept confidential?**

To ensure confidentiality, only the research team will have access to the demographic information, audio recordings and transcribed focus group data. The audio recordings will be transcribed verbatim by the student. All personal details that might identify any participants will be removed upon transcription. The transcripts will be uploaded into a password-protected database and once the analysis of the transcribed interviews is complete, the audio recordings will be destroyed. Participants will be identified by a participant number only. We would like to be able to quote what you say in reports or publications. We will make sure that your anonymity is protected, but if you do not wish us to quote you, please tell us.

The information that you provide will be used to write a dissertation for the fulfilment of the Doctorate in Clinical Psychology and may also be used to write academic papers to be published in peer-reviewed journals and in presentations at conferences. If you would like a summary of the results, please email the supervisor Dr Mark Hudson (Mark.Hudson@nottingham.ac.uk) for a copy.

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We will follow ethical and legal practice and all information will be handled in confidence. Under UK Data Protection laws, the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information and to read our privacy notice at: <https://www.nottingham.ac.uk/utilities/privacy.aspx>

We would like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. At the end of the project, all raw data will be kept securely by the University under the terms of its data protection policy after which it will be disposed of securely. The data will not be kept elsewhere.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the email addresses above.

#### **Who is organising and funding the research?**

This research is sponsored by the University of Nottingham and is being funded by Health Education England (HEE).

#### **Who has reviewed the research?**

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Nottingham Division of Psychology and Applied Psychiatry Research Ethics Committee.

#### **What if there is a problem?**

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the

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Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee [rita.gohil@nottingham.ac.uk](mailto:rita.gohil@nottingham.ac.uk) who will pass your query to the Chair of the Committee.

If you remain unhappy and wish to complain formally, you should then contact the Faculty of Medical and Health Sciences Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: [FMHS-ResearchEthics@nottingham.ac.uk](mailto:FMHS-ResearchEthics@nottingham.ac.uk)

We believe there are no known risks associated with this research study; however, as with any online activity the risk of a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous.

#### Further information and contact details

Fran Kemp  
Division of Psychiatry & Applied Psychology  
University of Nottingham  
YANG Fujia Building, B Floor  
Jubilee Campus  
Wollaton Road  
Nottingham  
NG8 1BB  
Email: [Francesca.Kemp@nottingham.ac.uk](mailto:Francesca.Kemp@nottingham.ac.uk)

Assistant Professor Mark Hudson  
Division of Psychiatry and Applied Psychology  
University of Nottingham  
Yang Fujia Building, B Floor  
Jubilee Campus  
Wollaton Road  
Nottingham  
NG8 1BB  
Email: [mark.hudson@nottingham.ac.uk](mailto:mark.hudson@nottingham.ac.uk)

Professor Thomas Schröder  
Division of Psychiatry and Applied Psychology  
University of Nottingham  
Yang Fujia Building, B Floor  
Jubilee Campus  
Wollaton Road  
Nottingham  
NG8 1BB  
Email: [thomas.schroder@nottingham.ac.uk](mailto:thomas.schroder@nottingham.ac.uk)

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## Appendix H

### Focus Group Guidelines



#### **GROUP GUIDELINES** (Final version 1.0: 17/02/2023)

**Title of Study: Developing a compassion-based intervention for parents of autistic children**

At the start of the meeting, we will all discuss the following group guidelines, to agree how we will use the time.

If you feel unsure about any of the below, you are welcome to ask the primary researcher in advance of the meeting.

If there are any extra rules that you would like to add to our list, you can bring this to the group, and we will discuss them together.

- Participation in the focus group is voluntary.
- It's alright to abstain from discussing specific topics if you are not comfortable.
- All responses are valid—there are no right or wrong answers.
- Please respect the opinions of others even if you don't agree.
- Try to stay on topic; we may need to interrupt so that we can cover all the material.
- Speak as openly as you feel comfortable.
- Avoid revealing very detailed information about your personal experiences that you may not feel comfortable with other people knowing.
- Please protect others' privacy by not discussing details outside the group
- You can choose whether you want to attend with your camera turned on or off
- You can choose in advance if you want to join using a pseudonym (fake name).

Other rules you may wish to discuss at the start of the meeting:

.....

.....

.....

.....

.....

.....

## Appendix I

### Consent Form for Parents



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**School of Medicine**  
University of Nottingham  
Medical School  
Nottingham  
NG7 2UH

## Participant Consent

*Interactive form for online consent*

**STUDENT RESEARCH PROJECT ETHICS REVIEW**  
Division of Psychiatry & Applied Psychology

Project Title: **Developing a compassion-based intervention for parents of autistic children**  
Researcher: **Francesca Kemp**  
Supervisors: **Dr Mark Hudson, Prof. Thomas Schröder, Dr Corinne Gale**  
Ethics Ref: **3003**

Have you read and understood the Participant Information? Yes No

Do you agree to take part in two focus groups that will be audio recorded and about gathering your views on how to adapt an existing psychological intervention for parents of autistic children? Yes No

Do you know how to contact the researcher if you have questions about this study? Yes No

Do you understand that you are free to withdraw from the study without giving a reason? Yes No

Do you understand that once you have taken part it may not be technically possible to withdraw your data? Yes No

Do you give permission for your data from this study to be shared with other researchers in the future provided that your anonymity is protected? Yes No

Do you understand that non-identifiable data from this study including quotations might be used in academic research reports or publications? Yes No

I confirm that I am 18 years old or over Yes No

---

**By selecting 'Yes', I indicate that I understand what the study involves, and I agree to take part. I consent to take part in this research study.** Yes No

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\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

2 copies: 1 for participant, 1 for the project notes

Participant contact email address used for Microsoft Teams meeting invitation link:

\_\_\_\_\_

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## Appendix J

### Consent Form for Clinical Psychologists



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**School of Medicine**  
University of Nottingham  
Medical School  
Nottingham  
NG7 2UH

## Participant Consent

**STUDENT RESEARCH PROJECT ETHICS REVIEW**  
Division of Psychiatry & Applied Psychology

Project Title: **Developing a compassion-based intervention for parents of autistic children**  
Researcher: **Francesca Kemp**  
Supervisors: **Dr Mark Hudson, Prof. Thomas Schröder, Dr Corinne Gale**  
Ethics Ref: **3003**

Have you read and understood the Participant Information? Yes No

Do you agree to take part in an expert panel that will be audio recorded and about gathering your views about adapting a compassionate mind training psychological intervention for parents of autistic children? Yes No

Do you know how to contact the researcher if you have questions about this study? Yes No

Do you understand that you are free to withdraw from the study without giving a reason? Yes No

Do you agree to maintain the confidentiality of the information discussed by all participants and researchers during the expert panel? Yes No

Do you give permission for your data from this study to be shared with other researchers in the future provided that your anonymity is protected? Yes No

Do you understand that non-identifiable data from this study including quotations might be used in academic research reports or publications? Yes No

I confirm that I am 18 years old or over Yes No

---

**By selecting 'Yes', I indicate that I understand what the study involves, and I agree to take part. I consent to take part in this research study.** Yes No

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\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person taking consent      Date                      Signature

2 copies: 1 for participant, 1 for the project notes

Participant contact email address used for Microsoft Teams meeting invitation link:

\_\_\_\_\_

## Appendix K

### Debrief Letter for Parents



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Medical School  
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## Debrief Form

### STUDENT RESEARCH PROJECT ETHICS REVIEW Division of Psychiatry & Applied Psychology

Project Title: **Developing a compassion-based intervention for parents of autistic children**

Researcher: **Francesca Kemp (Francesca.Kemp@nottingham.ac.uk)**

Chief Investigator: **Dr Mark Hudson (Mark.Hudson@nottingham.ac.uk)**

Secondary Supervisor: **Prof. Thomas Schröder**

Field Supervisor: **Dr Corinne Gale**

Ethics Ref: **3003**

Thank you for your participation in this research study.

#### **What was the purpose of this study?**

This study aimed to gather participant's feedback to support development of a new guided self-help intervention for parents of autistic children. We hope to later trial the developed intervention and estimate that this could help to improve parents' self-compassion and reduce their stress. The intervention will be based on Compassion Focused Therapy (CFT), which is designed to help people who experience problems like shame and self-criticism. This study is being carried out for educational purposes by a student on the Doctorate in Clinical Psychology and the findings will be written up as part of a dissertation.

#### **For more information**

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee [rita.gohil@nottingham.ac.uk](mailto:rita.gohil@nottingham.ac.uk) who will pass your query to the Chair of the Committee.

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If you feel concerned about anything you have talked about, please visit your GP as your first port of call.

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**Support programs for parents:** To find your local licensed support team, please check the National Autistic Society online directory:

<https://www.autism.org.uk/what-we-do/support-in-the-community/family-support/earlybird-teams>

**Charity Organisations:** There are many local, regional and national charities about Autism in the UK. These can include lots of useful resources, online forums and telephone support lines. Here are a couple to get you started:

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Ambitious about Autism: <https://www.ambitiousaboutautism.org.uk/>

**Other useful links (not autism specific):**

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Mind: <https://www.mind.org.uk/>

NSPCC support for parents with mental health difficulties:

<https://www.nspcc.org.uk/keeping-children-safe/support-for-parents/mental-health-parenting/>

Mental health services:

NHS help for families of autistic people: <https://www.nhs.uk/conditions/autism/autism-and-everyday-life/help-for-families/>

You could contact your local GP.

You could find a local NHS urgent mental health helpline (England only):

<https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>

Samaritans: <https://www.samaritans.org/> tel: 116 123

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## Appendix L

### Interview Schedule for Focus Group One

| Question                                                                                                                                     | Prompts                                                                                                                                                                                                                                                                                                                                                                                                                          |
|----------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. What are your thoughts about the first chapter of the workbook, which introduced compassionate mind training and the theory behind this?  | <i>How useful is the content covered?</i><br><i>How much does this relate to your experience of being a parent of an autistic child?</i><br><i>How easy to read was content covered?</i><br><i>How understandable was the areas discussed?</i><br><i>How did you find the length of the content covered?</i><br><i>How long do you think it would take a parent to be able to read and digest the content from this chapter?</i> |
| 2. What are your thoughts about the second chapter of the workbook, which focused on the role of parenthood and relating this to compassion? | <i>How useful is the content covered?</i><br><i>How much does this relate to your experience of being a parent of an autistic child?</i><br><i>How easy to read was content covered?</i><br><i>How understandable was the areas discussed?</i><br><i>How did you find the length of the content covered?</i><br><i>How long do you think it would take a parent to be able to read and digest the content from this chapter?</i> |
| 3. What are your thoughts about the third chapter, which considered how to prepare for practice and troubleshooting possible problems ahead? | <i>How useful is the content covered?</i><br><i>How much does this relate to your experience of being a parent of an autistic child?</i><br><i>How easy to read was content covered?</i><br><i>How understandable was the areas discussed?</i><br><i>How did you find the length of the content covered?</i><br><i>How long do you think it would take a parent to be able to read and digest the content from this chapter?</i> |
| 4. What are your thoughts about the final chapter, which discussed different                                                                 | <i>How useful is the content covered?</i>                                                                                                                                                                                                                                                                                                                                                                                        |

| Question                                                                                                                                                                                                                                                                                               | Prompts                                                                                                                                                                                                                                                                                                                                                                                                    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>compassionate mind practices?</p>                                                                                                                                                                                                                                                                   | <p><i>How much does this relate to your experience of being a parent of an autistic child?</i></p> <p><i>How easy to read was content covered?</i></p> <p><i>How understandable was the areas discussed?</i></p> <p><i>How did you find the length of the content covered?</i></p> <p><i>How long do you think it would take a parent to be able to read and digest the content from this chapter?</i></p> |
| <p>5. What was your experience of the audio tracks that accompany the workbook?</p>                                                                                                                                                                                                                    | <p><i>How could these be improved?</i></p>                                                                                                                                                                                                                                                                                                                                                                 |
| <p>6. As the workbook stands, the compassionate practices are only discussed in the fourth chapter, and so would be provided in the fourth week. However, I am thinking about adding a different practice to each week, for parents to engage with possibly daily. What are your thoughts on this?</p> |                                                                                                                                                                                                                                                                                                                                                                                                            |
| <p>7. How could we make the resource more accessible?</p>                                                                                                                                                                                                                                              | <p><i>Where could we possibly shorten sections?</i></p> <p><i>Where could we make aspects more ASD specific?</i></p>                                                                                                                                                                                                                                                                                       |
| <p>7. How could we make the resource more accessible?</p>                                                                                                                                                                                                                                              | <p><i>We were thinking about making an accompanying video for the first chapter, which would show me introducing the parent to the resources and talking through the psychoeducation from the chapter. What are your thoughts on this?</i></p>                                                                                                                                                             |
| <p>8. Are there any other comments that you wanted to make about the workbook that we have not yet discussed?</p>                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                            |

## Appendix M

### Interview Schedule for Focus Group Two

| Question                                                                                                                                                                                                                  | Prompts                                                                                                                                                                                                                                  |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. What are your thoughts about the adaptations made to the workbook?                                                                                                                                                     | <i>In chapter one?</i><br><i>In chapter two?</i><br><i>In chapter three?</i><br><i>In chapter four?</i><br><i>In chapter five?</i><br><i>In chapter six?</i>                                                                             |
| 2. Do any parts seem as though they would work particularly well?                                                                                                                                                         | <i>What do you think makes this work well?</i>                                                                                                                                                                                           |
| 3. Which parts felt more difficult to engage with?                                                                                                                                                                        | <i>Were there any sections that were difficult to understand?</i><br><i>Was any of it too wordy or lengthy?</i><br><i>Were there any sections that felt less relatable to your own experiences as a parent of an autistic child/ren?</i> |
| 4. How could this be improved?                                                                                                                                                                                            | <i>(relating specifically to any points raised in question three)</i>                                                                                                                                                                    |
| 5. As the resource now looks, how feasible would it be for a parent to engage in each chapter over a week? What are your thoughts about parents engaging in the exercises listed at least once daily during the research? | <i>What aspects about the intervention informed your decision?</i>                                                                                                                                                                       |
| 6. As a parent of an autistic child, if you were looking online or speaking with Autism organisations and you came across this self-help book, would this be something that you would be interested in using?             | <i>What aspects about the intervention informed your decision?</i>                                                                                                                                                                       |

## Appendix N

### Interview Schedule for Focus Group Three

| Question                                                                                                                                                                           | Prompts                                                                                                                                                |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. How feasible do you think offering CFT self-help to parents of children with ASD via the proposed materials will be?                                                            | <i>Tell us more about that (can you provide any examples from your practice?).</i><br><br><i>What barriers do you think we would need to overcome?</i> |
| 2. What might be the advantages of CFT for parents via this resource, compared to other recommended interventions to treat parental mental health in a non-clinical population?    | <i>For parents?</i><br><br><i>For services?</i>                                                                                                        |
| 3. What might be the disadvantages of CFT for parents via this resource, compared to other recommended interventions to treat parental mental health in a non-clinical population? | <i>For parents?</i><br><br><i>For services?</i><br><br><i>Via (guided) self-help?</i>                                                                  |
| 4. Based on your experience, what further recommendations would you make for adapting this resource and delivering it to parents of autistic children?                             | <i>Can you give any specific examples from your practice?</i>                                                                                          |
| 5. How appropriate do you think that CMT is for parents?                                                                                                                           | <i>What barriers might the research team/future therapist need to overcome?</i>                                                                        |
| 6. We have attempted to ensure that adaptations and recommendations maintain consistency with the theory underpinning CFT. To what extent do you think this has been achieved?     | <i>What recommendations could you make around making the resource more consistent with CFT?</i>                                                        |
| 7. Do you have any further feedback that you would like to provide?                                                                                                                |                                                                                                                                                        |

## Appendix O

### Codebook for Directed Content Analysis

| Theme                        | Sub-theme                    | Description of Code                                                                                                                                                                                                                                                                                        |
|------------------------------|------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Content Modifications</b> | <i>Adding Elements</i>       | (Intervention modules or activities): Additional materials or activities are inserted that are consistent with the fundamentals of the intervention (e.g., adding further exercises)                                                                                                                       |
|                              | <i>Lengthening-Extending</i> | (Pacing/timing): A longer amount of time than prescribed by the manual/ protocol is spent to complete intervention or intervention sessions (e.g., greater spacing between sessions, longer sessions, more sessions, or spending more time on one or more modules/activities or concepts)                  |
|                              | <i>Loosening structure</i>   | Elements intended to structure intervention sessions do not occur as prescribed in the manual/protocol (e.g., the 'check-in' at the beginning of a group intervention is less formally structured; clinician does not follow an agenda that was established at the beginning of the session).              |
|                              | <i>Removing elements</i>     | (Removing/skipping intervention modules or components): Particular elements of the intervention are not included (e.g., leaving out a demonstration, psychoeducation topic, or example)                                                                                                                    |
|                              | <i>Re-ordering modules</i>   | Modules/activities or concepts are completed in a different order from what is recommended in the manual/protocol. This code would not be applied if the protocol allows flexibility in the order in which specific modules or interventions occur.                                                        |
|                              | <i>Shortening-Condensing</i> | (Pacing/timing): A shorter amount of time than prescribed is used to complete the intervention or intervention sessions (e.g., shorter spacing between sessions, or shortening sessions, offering fewer sessions, or going through particular modules or concepts more quickly without skipping material). |



| <b>Theme</b>                                 | <b>Sub-theme</b>    | <b>Description of Code</b>                                                                                                                                                                                                                                                                                       |
|----------------------------------------------|---------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Contextual Modifications</b>              | <i>Spreading</i>    | E.g. spreading out psychosocial or educational content intended for a single meeting or session over multiple sessions, as this may occur when an individual requires more time to understand content or when unforeseen or emergent issues need to be addressed during a given session.                         |
|                                              | <i>Tailoring</i>    | Any minor change to the intervention that leaves all the major intervention principles and techniques intact while making the intervention more appropriate, applicable or acceptable (e.g., modifying language, creating slightly different versions of handouts or homework assignments, cultural adaptations) |
|                                              | <i>Format</i>       | Changes are made to the format or channel of treatment delivery (e.g., a treatment originally designed to be used one-on-one that is now delivered in a group format).                                                                                                                                           |
|                                              | <i>Personnel</i>    | The intervention is being delivered by personnel with different characteristics (e.g., a treatment originally designed to be administered by a mental health professional is now delivered by clergy).                                                                                                           |
|                                              | <i>Population</i>   | An intervention that was specifically developed to target a particular population is being delivered to a different population than originally intended (e.g., an intervention developed for patients with Personality Disorder is now being delivered to individuals with Substance Dependence)                 |
| <b>Training and Evaluation Modifications</b> | <i>Setting</i>      | The intervention is being delivered in a different setting or location (e.g., a treatment originally designed to be used in a mental health clinic setting that is now delivered in primary care)                                                                                                                |
|                                              | <i>Evaluation</i>   | Suggestions influencing how the intervention is planned to be evaluated.                                                                                                                                                                                                                                         |
|                                              | <i>Facilitators</i> | Suggestions around who could facilitate the intervention (e.g., facilitating guided support).                                                                                                                                                                                                                    |

| Theme                                            | Sub-theme                                | Description of Code                                                                                                                                                                                                                                                                  |
|--------------------------------------------------|------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Implementation and Scale-up Modifications</b> | <i>Implementation</i>                    | Suggestions for modifications made to the strategies used to implement or spread the intervention in the real world.                                                                                                                                                                 |
| <b>Reasons for Adaptations</b>                   | <i>Increase reach or engagement</i>      | Adaptations made to increase the scope of who the intervention is accessible to, so that more people can engage (e.g. where advertised, making accessible, broadening eligibility criteria).                                                                                         |
|                                                  | <i>Increase retention</i>                | Adaptations made to decrease the likelihood that recipients will drop out partway through and facilitate ongoing engagement with the resource.                                                                                                                                       |
|                                                  | <i>Improve feasibility</i>               | Adaptations made to make the intervention more possible to engage with and complete in the specified timescale.                                                                                                                                                                      |
|                                                  | <i>Improve fit with recipients</i>       | Adaptations made to make the intervention more relatable and acceptable for the target population group (if adaptation relates to making feasible due to PAC contextual factors, code “improve feasibility”, if specifically adding to reduce attrition, code “increase retention”). |
|                                                  | <i>Address cultural factors</i>          | Adaptations made to address intervention fit whilst considering specific cultural factors within parents of autistic children (e.g., cultural understanding of ASD, language differences).                                                                                           |
|                                                  | <i>Improve effectiveness or outcomes</i> | Adaptations made to increase the effectiveness of the intervention or to increase the likelihood of positive outcomes and reduce the likelihood of adverse outcomes.                                                                                                                 |
|                                                  | <i>Reduce cost</i>                       | Adaptations made to specifically reduce the associated costs to facilitate the intervention.                                                                                                                                                                                         |
|                                                  | <i>Increase recipient satisfaction</i>   | Adaptations made to make the intervention feel more satisfying or enjoyable to experience.                                                                                                                                                                                           |

## Appendix P

### Example Coding from Directed Content Analysis

*Example one (FG1):*

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|
| <p><b>Rachel:</b> I think that, yes it is hard, especially say for example if your young person doesn't go to school or isn't able to access school or anything outside of the house and likely sort of isolated hangs the different options, but I think that in-person support, (sigh) whether that's that they come into your home, or whether they do it, um in the different ways of contacting you whether it's by email or whatever, it's going to make you more likely to take part in this? Um, if you, as a parent anyway you're not going to prioritise helping yourself because you just don't, your priority is helping your children, and so if you haven't got someone there talking to you about supporting you with it, it's doubtful that you'll do it. Um, you know because it's at the bottom of your list of priorities. I was thinking, when I was thinking about it earlier, that maybe it could be delivered as like a group activity, um, again it's the sort of childcare issues that you're gonna have, and I think it's having that, it's making sure it's accessible to people who have got different needs themselves, but also their children have different needs and it's, there's no one answer fits all, absolutely not, but I think having options are gonna encourage people to take part in this more than just saying 'this is how it's delivered, that's that'.</p> | <p>Format – Increase<br/>Reach or Engagement</p> <p>Format – Increase<br/>Reach or Engagement</p> <p>Format – Increase<br/>Reach or Engagement</p> |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|

*Example two (FG2):*

**Rachel:** And I know it, this sounds a bit, I'm going to say it anyway, it probably sounds a bit weird, but you know the looking like speech bubbles but they're all spiky on the outside, well ... I don't like the spikiness (laughs)

**Moderator:** Okay!

**Rachel:** Because it's, for me I look at it and BAM, it's that to me, it's like, sharp and I don't know, but, I also have a neurodiverse brain and that may be my perception of it, but my, um, I just look at those zig-zags and it's like, anger or fire or something like that, I don't know, and that could be totally irrelevant, and it's just a very minor point, but that's how it was to me

**Claire:** I don't like it either, it reminds me of school, when I was in school as a child and the board, they'd have those cut-outs like that, and in much more bright colours with things shoved on the boards, so that's like almost - I didn't have the best time in school – triggering for me, seeing that back there like that

**Moderator:** Okay

**Claire:** I just found it a bit visually overwhelming for me personally, on top of that

Tailoring – increase recipient satisfaction

Tailoring – increase recipient satisfaction

Tailoring – increase recipient satisfaction

Tailoring – increase recipient satisfaction

*Example three (CP written feedback):*

Polly: I love the fact that you've created this workbook and I think there is a really valuable place for this resource to support our parents. Very well done and I can see all of the hard work and effort that you've put into creating this resource. Wow! Here are some general comments but I've also put comments relating to these in the document itself.

Many of our parents are neurodiverse and I wondered about including more imagery / visual information and

Tailoring – improve fit with recipients

chunking sections more often. I really like it when you do use visuals to support the explanations.

I really like how you've used colours to make it more accessible. I would possibly incorporate more colour generally to make it visually appealing. I work for [service] one day a week and can send you some of their booklets as their use of colour is great.

I would probably make some of the language less formal and take out scientific terms (like fight, flight, freeze) unless they are explained to people using more simple language.

You have used less formal language in some of the sections and I really like that-it makes the workbook feel relatable. I would make the language feel less formal (like it's a cuppa and chat feeling) so people feel the warmth and support through the language used.

I think the first chapter is very dense in terms of the concepts being covered and I worry that it may lead to some parents feeling over-whelmed. I was wondering whether all the concepts need to be included in the first chapter or whether some could be weaved in later on?

I love the use of incorporating the regular practices and linking it with the audio practices. I would consider having reflective sections straight after exercises so people can remember what it was that they experienced.

I wonder with the sending out compassion to others whether it may help to have a bit on sending out compassion to other parents of children with autism?

I did wonder about a compassionate object exercise so parents have something they can carry around with them?

I love the fact that you've ended with compassionate letter-writing and included a sample for parents too.

Very well done on all your hard work!!

Tailoring – increase recipient satisfaction

Tailoring – improve reach or engagement

Tailoring – increase recipient satisfaction

Spreading elements – improve feasibility

Adding elements – improve effectiveness/outcomes

Tailoring – improve fit with recipients

Adding elements – improve effectiveness/outcomes

## Appendix Q

### Inter-rater Reliability Check Calculations

| Code: "Tailoring"   |               | Coder 2             |
|---------------------|---------------|---------------------|
| Coder 1             | Assigned code | Did not assign code |
| Assigned Code       | 9             | 3                   |
| Did not assign code | 0             | 10                  |

| Code: "Tailoring"   |                                         | Coder 2                                  |
|---------------------|-----------------------------------------|------------------------------------------|
| Coder 1             | Assigned code                           | Did not assign code                      |
| Assigned Code       | $P_{11} = 9/21 =$<br>0.4285714285714286 | $P_{12} = 3/21 =$<br>0.1428571428571429  |
| Did not assign code | $P_{21} = 0/21 =$<br>0                  | $P_{22} = 10/21 =$<br>0.4761904761904762 |

$$\begin{aligned}
 P_o &= P_{11} + P_{22} \\
 &= 0.4285714285714286 + 0.4761904761904762 \\
 &= \mathbf{0.9047619047619048}
 \end{aligned}$$

$$\begin{aligned}
 P_E &= (P_{11} + P_{21})(P_{11} + P_{12}) + (P_{12} + P_{22})(P_{21} + P_{22}) \\
 &= (0.4285714285714286+0)(0.4285714285714286+0.1428571428571429) + \\
 &\quad (0.1428571428571429+0.4761904761904762)(0+0.4761904761904762) \\
 &= 0.4285714285714286*0.5714285714285715 + \\
 &\quad 0.6190476190476191*0.4761904761904762 \\
 &= 0.2448979591836735 + 0.2947845804988662 \\
 &= \mathbf{0.5396825396825397}
 \end{aligned}$$

$$\begin{aligned}
 k &= (P_o - P_E)/(1 - P_E) \\
 &= (0.9047619047619048 - \mathbf{0.5396825396825397})/(1 - \mathbf{0.5396825396825397}) \\
 &= 0.3650793650793651/0.4603174603174603 \\
 &= \mathbf{0.79}
 \end{aligned}$$

**Calculating pooled Kappa Coefficient**

| <b>Coding Type</b>              | <b>Code</b>                   | <b>All assigned</b>         | <b>All did not assign</b> | <b>Coder 1 assigned only</b> | <b>Coder 2 assigned only</b> | <b>P<sub>o</sub></b> | <b>P<sub>E</sub></b> |                    |
|---------------------------------|-------------------------------|-----------------------------|---------------------------|------------------------------|------------------------------|----------------------|----------------------|--------------------|
| <b>Type of Adaptation</b>       | Tailoring Elements            | 11                          | 19                        | 0                            | 0                            | 1                    | 0.5355555555555556   |                    |
|                                 | Removing Elements             | 3                           | 28                        | 0                            | 0                            | 1                    | 0.8251821019771072   |                    |
|                                 | Personnel                     | 1                           | 30                        | 0                            | 0                            | 1                    | 0.9375650364203954   |                    |
|                                 | Format                        | 8                           | 23                        | 0                            | 0                            | 1                    | 0.6170655567117586   |                    |
|                                 | Population                    | 3                           | 28                        | 0                            | 0                            | 1                    | 0.8251821019771072   |                    |
|                                 | Loosening Structure           | 1                           | 30                        | 0                            | 0                            | 1                    | 0.9375650364203954   |                    |
|                                 | Spreading Content             | 1                           | 30                        | 0                            | 0                            | 1                    | 0.9375650364203954   |                    |
|                                 | Adding Elements               | 2                           | 29                        | 0                            | 0                            | 1                    | 0.8792924037460978   |                    |
|                                 | Shortening or Condensing      | 1                           | 30                        | 0                            | 0                            | 1                    | 0.9375650364203954   |                    |
|                                 | <b>Reasons for Adaptation</b> | Increase reach/ engagement  | 9                         | 20                           | 2                            | 0                    | 0.9354838709677419   | 0.5608740894901145 |
|                                 |                               | Address cultural factors    | 4                         | 27                           | 0                            | 0                    | 1                    | 0.7752341311134236 |
|                                 |                               | Improve fit with recipients | 7                         | 23                           | 0                            | 1                    | 0.9677419354838709   | 0.6326742976066596 |
|                                 |                               | Increase retention          | 4                         | 25                           | 1                            | 1                    | 0.9354838709677419   | 0.7294484911550468 |
| Improve feasibility             |                               | 3                           | 27                        | 0                            | 1                            | 0.967741935483871    | 0.7710718002081166   |                    |
| Improve effectiveness/ outcomes |                               | 1                           | 0                         | 0                            | 30                           | 1                    | 0.9375650364203954   |                    |

***Pooled Kappa calculation (De Vries et al., 2008)***

**Mean  $P_O$**  = 0.9870967741935487

**Total  $P_E$**  = 0.7892937141095307

$$k_{pooled} = \frac{\bar{P}_O - \bar{P}_E}{1 - \bar{P}_E}$$

**$K_{pooled}$** : 0.94



## Appendix R

### Excerpt from Database for Tracking Adaptations

| Data Collection Stage | Implemented? | Category of adaptation | Type of adaptation | Reason for adaptation          | Relating to                                        | Details (direct quote)                                                                                                                                                                                                                                                                                           | Action                                                                                                                                             | Reasons                  | Fidelity consistent? |
|-----------------------|--------------|------------------------|--------------------|--------------------------------|----------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|----------------------|
| FG1                   | Not yet      | Contextual             | Format             | To address cultural factors    | Whole workbook format                              | we need to make sure that it is accessible to everybody, to enable them to have access, you know whether that's different types of speaker, we need different languages, different ways of presenting the information, that all needs to be available                                                            | Not feasible to complete in current stage of research project, but added as future research direction (use of video format for whole intervention) |                          | N/A                  |
| FG1                   | Yes          | Contextual             | Population         | Improve feasibility            | Experiential exercises                             | diagnosed when she was 6, but, I was also thinking about, um, timewise about being able to do the actual practice, and I was thinking actually I'd ask her to have a go at doing it with me, um as also to kind of give me the time to do it                                                                     | Added this ideas as a tip in week one                                                                                                              | Access to resources      | Yes                  |
| FG1                   | Yes          | Content                | Spreading          | Improve effectiveness/outcomes | Placement of experiential exercises in workbook    | whether actually it could be good to have something for each section of a workbook so people can practice and gradually build up skills                                                                                                                                                                          | Exercises split up into weeks 1-6                                                                                                                  | Cognitive capacity       | Yes                  |
| FG1                   | Yes          | Content                | Tailoring          | Improve fit with recipients    | Description on completing exercises                | the actual instruction for carrying it out for what you should do could be a bit, a bit more descriptive maybe, than it is at the moment, I know it has to be open to you being able to do it when you can, but it's kind of like that two week programme, then you've finished, okay so am I compassionate now? | information about the hoped outcome of the intervention pre-chapter one.                                                                           | Motivation and readiness | Yes                  |
| FG1                   | Yes          | Content                | Adding Element     | Increase reach or engagement   | Addition of timetable                              | it might actually be helpful to have a suggested sort of timetable if you like, or something like that at the beginning maybe, just to say 'well we'd recommend that you take this amount of time each week, or you could do it this way' just as a guide                                                        | Timetable added pre-chapter one                                                                                                                    | Motivation and readiness | Yes                  |
| FG1                   | Yes          | Content                | Addine Element     | Increase reach or enaesement   | Pre-chapter one include information about duration | maybe at the beginning of the booklet there's something which tells you how long it's gonna take you [...] if perhaps in the beginning it said you know, it's going to take a couple of your minutes every day, then maybe that would also encourage people to, to set into it.                                  | Timines added to timetable                                                                                                                         | Motivation and readiness | Yes                  |

## Appendix S

### Excerpt from Table for Decision-Making during Adaptation

| Feedback type and adaptation goal               | Feedback from FG1                                                                                                                         | Section it relates to | Criterion 1: Alignment with core functions/ intervention fidelity? | Criterion 2: Goal/ rationale for adaptation addressing fit?  | Criterion 3: Systematic adaptation process with consideration to impact on outcomes?     | Criterion 4: Proactive adaptation made due to anticipated obstacles? | Actions from research team                                                           |
|-------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|--------------------------------------------------------------------|--------------------------------------------------------------|------------------------------------------------------------------------------------------|----------------------------------------------------------------------|--------------------------------------------------------------------------------------|
| Content Modification:<br><i>Adding Elements</i> | Start off with who this is aimed for, how this relates to meet the needs of a parent, how it can help, what this will do and why to do it | Beginning of workbook | Aligns with core functions and supplements intervention fidelity   | Increasing intervention coherence and parent's self-efficacy | Yes – felt to support PAC informed choice to engage with intervention, positive outcomes | Yes – to ensure criterion 2                                          | <i>“A bit about this book”</i> added pre-chapter one to detail requested information |
| Content Modification:<br><i>Adding Elements</i> | Add something about it helping your sleep, that would be a big sell point                                                                 | Beginning of workbook | <b>Not a core intervention target</b>                              | N/A                                                          | N/A                                                                                      | N/A                                                                  | Not implemented                                                                      |
| Content Modification:<br><i>Adding Elements</i> | Add a table to recommend how long to do it each week as a guide                                                                           | Beginning of workbook | Aligns with core functions and supplements intervention fidelity   | Increasing intervention coherence and parent's self-efficacy | Yes – felt to support PAC informed choice to engage with intervention, positive outcomes | Yes – to ensure criterion 2                                          | Table added to detail requested information in <i>“a bit about this book”</i>        |

## Appendix T

### Example Indexing from Framework Analysis

Example one (FG1):

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                              |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Rachel:</b> I didn't want to read it, um, I thought it was far too wordy, I thought the, the words that were used were not relevant, necessarily, I thought it's not accessible, um, there's a lot of words in there, I think it's, I think it's valuable, what it's telling you, and I think it's important that you understand the reasons why this, these exercises etcetera will be happening, however, you know, when are you going to have time to read 27 pages before you even start the practice? I've no idea. You know and it was, it's not engaging, it's not, you know, let's look, I just don't think it's accessible for parents, never mind parents of autistic children that have no time, no energy, and you know, if you think about the audience that you're giving it to, um, many parents, and I'm generalising here because I don't know the exact figures, many parents of autistic children have their own, could have their own mental health issues, their diagnosis of autism, they could have learning difficulties, none of this is accessible to people like that, it's very, it's aimed at a very very white middle class, educated group of people, and even though I suppose I happen to be one of them, I still wouldn't have gone to read this as it was too long, and it was too wordy, so that's, I know I sound really negative about it because I think what it, the actual programme is valuable, but honestly I got to sort of page 2 and I thought I'm not, I'm not really interested in continuing any further really, I just couldn't do it, just too much for me | Accessibility considerations<br><br>Value of CMT<br><br>Parental constraints<br><br>Accessibility considerations<br>Parental constraints<br>Parents' learning support needs<br><br>Accessibility considerations<br>Perceived target audience<br>Accessibility considerations<br>Value of CMT<br>Accessibility considerations |
| <b>Moderator:</b> Okay, I think they are really valuable points [Rachel]... I wondered what were other people's thoughts?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                              |

Did others feel similarly about the first chapter, or the book as a whole, or maybe differently?

**Mo:** I thought the like you say what is compassion, understanding our mind, all that, it is a lot to read though yeah, but at the beginning yeah, maybe it could be a bit shortish paragraphs maybe? Yeah, I don't know or, a bit more, um, more pictures or things like that, I don't know

**Moderator:** Okay

**Mo:** Some more visuals and stuff. But I did find it interesting, um, yeah but as I think yeah for people that are educated, and things like that, I think they would find it, like say, say people who are like reading a lot, they would like it, you'd have like a balance, yeah

Accessibility  
considerations

Value of CMT

Perceived target  
audience

*Example two (FG2):*

**Rachel:** Tone-wise when I was reading it, just, it was more ... it was more of a conversation, and it was, it was more like the person who wrote it actually understood that sometimes life doesn't go as planned, and that's okay, and it, the uh, tone was more reassuring and it was less ... instructional. The first time round, it was like 'you do this, you do this, you do this' whereas now it was, it's more about, you know, 'have a go at doing this, try and do this, if you can't do it, that's okay don't worry, you can always come back' and I felt there was something that, um, I mean the first time I read it, I think we talked about, I know [Mo] was in the last group, we talked about how you kinda zoned out after a while, there was so much information that it was like 'I don't want to be bothered now', but this is more, it just seems more welcoming and friendly to me, anyway.

**Mo:** Yeah it's more better than it was before

Attitude towards  
intervention tone  
Needing to feel  
understood  
Attitude towards  
intervention tone  
Overcoming threat

Attitude towards  
intervention tone

Moderator: Thank you! I wonder, for any of the new faces who haven't seen the previous one, I wondered, what were your thoughts on the tone and how it was written?

**Josie:** I thought it was, I wrote down 'reassuring' as well actually, because several times throughout the whole book it says, there's a sentence that says 'this is not your fault, this is not your fault' and I found that, you know, no one ever really says that to you, so, and you do blame yourself for ... everything! So I thought that was really nice that that was included in the book, so I wrote down that the wording was very reassuring, as a parent.

**Moderator:** Okay, that's brilliant.

**Claire:** Yeah I liked that as well, I liked it was bold and highlighted as well so it's kinda, quite a statement there.

(pause)

**Moderator:** Did anybody have any different thoughts about...

**Rachel:** (interrupts) I ... (pauses speaking)

**Moderator:** Sorry [Rachel], you go ahead.

**Rachel:** Me again, I just think it's, it sounds now as if it comes from someone who has an understanding. I think the previous one was a bit like, we're telling you what to do because the theory says this is what you need to do, but this one is a bit more understanding as well I think, if someone, it's as if it's written by somebody who has some idea of what it's like to parent an autistic child, or at least know about autism from their everyday life rather than from what they've read.

Overcoming threat

Negative self-evaluation

Overcoming threat

Overcoming threat

Needing to feel understood

Example three (FG3):

**Tara:** Ooh sorry, I think maybe as, a level of, kind of, I do wonder if you have to maybe have a certain level of education to access it, I don't know (sigh) whether for some people it might be hard to access? And I don't think that's to do with how you've written it or anything like that, um, because even I was thinking, sometimes you have to be careful with abstract stuff or too much imagery, and that kind of thing with, especially if we're wondering if some of the parents might also be neurodivergent um, so I guess that, I don't know, there's something about how suitable is it, I'm not sure it would be an intervention that would be suitable for all people, do you know what I mean? Sorry I'm not articulating why I think that very well

**Polly:** I think, I think our experience from running the parent groups is like, these are some of the most squeezed parents, and the research shows that like, they're some of the most stressed parents aren't they? And I guess could really benefit from a CFT approach but on a practical sense, can then mean it feels like you just haven't got the headspace to access something, and then I guess the pull is when you've got regular appointments with a clinician (laughs) you've got a certain level of feeling like you've got to show up, whereas if it's more kind of self-directed, when, whether people might start off quite keen but then life takes over and day to day pressures takes over, and then it's really kind of hard to find the consistency with it, and almost whether it's like acknowledging that, and just saying you know, we get that for families that you know, there's times where it just feels crazy and so busy, and whether almost like they can put a pause on it like a breaker and come back to it? It's not a sense of failing as a parent, it's part of the course of trying to engage in

Perceived target audience

Parent's learning support needs

Applicability constraints

Parental constraints

Parental mental health

Parental constraints

Value of guided support

Parental constraints

Engagement dynamics

Challenges in parenting

Engagement dynamics

Overcoming threat

something alongside all the trials and tribulations of parenting children, and parenting children that might have particular struggles day to day as well, um, because with our parent group we've struggled haven't we over time guys to kind of sign up, and there's a different set of factors with that, perhaps about the group format as well, but yeah, I guess it's holding that in mind about how you pitch it.

(participants talking over one another)

Tara: Whoops, sorry. I wonder if um, having almost like, groups of, something where you can join a Facebook group or whatever it is, where there's other people doing it at the same time so you can get that kind of accountability check in type of thing, you know almost like you'd have with a book club or whatever, where you think "ooh I need to do that chapter", or you say to people oh did you try it this week, how did you find it, whatever it is? Um, whether that's a way of tapping into that kind of keeping you accountable or keeping your kind of enthusiasm even when times are tough kind of thing, I don't know if that's a rubbish idea.

Polly: I like that you see. I like that fact that you can tap into kind of potentially other parents going through similar stuff, and it's like "oh my god I've had a really shit week this week", sorry excuse the French, um, and then you can share that and bolster each other as well, um, because there is something isn't there about commonality and shared support networks going through the same thing but also I guess trying to tap into the same resource as well

Jan: I think it's a really important bit of work that's often missing from services because we're not really commissioned to do parent work, but actually, that's the work that often needs to be done, and I think parents aren't able to support their children with strategies if they can't find that compassion and they're burnt out, so being able to offer some kind of format, and I think this could lend itself nicely in lots of different ways in services, to do group work

Challenges in parenting

Parental constraints

Value of guided support

Value of guided support

Needing to feel understood

Gaps in services

Parental mental health

Value of CMT

## Appendix U

### Excerpt from Data Summary and Display in NVIVO14

| Theme 1 Challenges to Overcome |                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                 |
|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                | A : Competing demands and limited time                                                                                                                                                                                                                                                                                                       | B : Making it accessible for more                                                                                                                                                                                                                                                                                                                                                                                                  | C : Parents' expectations from intervention                                                                                                                                                                                                                                                                                                                                     |
| 1 : FG1-2023-07-14             | <p>Parents have limited time and energy to access workbook.</p> <p>Childcare responsibilities are a barrier to in-person and telephone support.</p> <p>Difficult to plan regular workbook use due to the unexpected happening.</p> <p>Difficult to find time to digest workbook content or do exercises when in crisis or survival mode.</p> | <p>All felt the resource was inaccessible for parents of autistic children as it was too wordy, needed cutting down, was too much to read, and that big words were off-putting. Need more punchy straplines and less long text.</p> <p>One described having reading fatigue from text and would have preferred video and infographics.</p> <p>Not accessible for parents with own mental health issues, learning disability or</p> | <p>Wanting answers for fixing the situation and helping.</p> <p>Unclear how this will be effective; how will this help me and my child?</p> <p>Prioritising child's wellbeing over self.</p> <p>Difficult to know when time is right for this intervention, where on diagnostic pathway are they?</p> <p>Questioning why parents need information about why the brain works</p> |
| 2 : FG2-2023-11-24             | <p>One questioned what to do if unexpectedly interrupted partway through practice.</p> <p>Only section felt a lot to read was time for practice transcripts.</p> <p>Chapter-by-chapter exercises preferred, less overwhelming considering the rest of the to-do list as a parent.</p>                                                        | <p>Not everybody is a parent, may be annoyed by feeling excluded by that term, what about foster carers etc.</p> <p>Need to think about everyone's minds who are reading this.</p> <p>Colours too bright in diagram, was painful to one.</p>                                                                                                                                                                                       | <p>Recipients might be used to other parenting models using similar colours as 3 circles</p> <p>Possibility of reading the last chapter first – congratulatory message offputting</p>                                                                                                                                                                                           |
| 3 : FG3-2024-02-22             | <p>Life might get in the way and parents may dip in and out of intervention.</p> <p>Some of the most stressed parents, with children that might have particular struggles too. May mean lack of headspace to access support.</p> <p>Importance of highlighting it's okay to pause and return.</p>                                            | <p>Recipients needing certain level of education to access, particularly if no guided support element.</p> <p>Inevitability of hurdles for different groups when creating intervention for the masses.</p> <p>Weaving psychoed through to make it accessible.</p>                                                                                                                                                                  | <p>[no data]</p>                                                                                                                                                                                                                                                                                                                                                                |



## Appendix V

### Example Descriptive Analysis Process

| Data       | Data Summary for Subtheme:<br><i>Competing demands and limited time</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Elements/<br>dimensions in<br>order identified                                                                                                                                                                                                                                                     | Emerging<br>Categories/<br>Classes                                                              |
|------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
| <b>FG1</b> | <p>No time to read workbook.<br/>Workbook inaccessible as parents of autistic children have no time or energy.<br/>No time to read workbook when you're at crisis point, which is when parents might ask for help.<br/>Helping myself by trying to stay alive and function, no time to do compassionate skills.<br/>Parenting an autistic child is difficult, workbook should be more concise.<br/>Couldn't access telephone support as would upset child.<br/>Couldn't access telephone support as would upset child.<br/>Hard to access in-person support due to childcare commitments.<br/>Childcare issues accessing groups.<br/>Parents won't use this if in survival mode.<br/>Difficulty finding time to digest workbook content. Liking when resource recognises lack of time.<br/>Parents have limited time, resource doesn't take this into account.<br/>If child doesn't want to go out, neither will you.<br/>Difficult to plan routine as the unexpected may happen.</p> | <p>Parents have no time or energy.<br/><br/>Parental mental health state.<br/><br/>Survival mode.<br/><br/>Supporting child's needs.<br/><br/>Childcare commitments preventing engagement out of house.<br/><br/>Lack of time to digest resource.<br/><br/>Unplanned events impacting routine.</p> | <p>Parental Constraints.<br/><br/>Parental Mental Health.<br/><br/>Challenges in Parenting.</p> |

| <b>Data</b> | <b>Data Summary for Subtheme:<br/><i>Competing demands and limited time</i></b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | <b>Elements/<br/>dimensions in<br/>order identified</b>                                                                                                                                                                                                                                                                        | <b>Emerging<br/>Categories/<br/>Classes</b>                                                                                                                 |
|-------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>FG2</b>  | <p>Only bit a lot to read was the time for practice sections, but appreciate it needs to be there</p> <p>Potential for unexpected chaos or crisis partway through exercises, what to do then?</p> <p>Chapter by chapter exercises better way to break it down, it's not a lot on top of everything else, just another thing on the to do list</p> <p>Overwhelm if exercises at back, wouldn't look at them.</p>                                                                                                                                                                                                                                                                                           | <p>Majority feels ok to read, time for practice a lot.</p> <p>Unexpected chaos distracting engagement.</p> <p>Little and often practices less overwhelming.</p>                                                                                                                                                                | <p>Accessibility considerations.</p> <p>Challenges in Parenting.</p> <p>Parental Mental Health.</p>                                                         |
| <b>FG3</b>  | <p>Get used to reading stuff as a professional, familiar with theory, but if others feel it's overwhelming, breaking it up is good idea.</p> <p>There will be times when life gets in the way and this gets benched, parents may dip in and out of this, it is part of life.</p> <p>Need to avoid making too cumbersome</p> <p>These are some of the most stressed parents, can mean it feels like they don't have the headspace to access something</p> <p>There's times where it feels so busy in families, it's okay to take a pause and come back to it</p> <p>Engaging with something alongside the trials and tribulations of parenting children who might have particular struggles day-to-day</p> | <p>Assumptions and professional familiarity with intervention components.</p> <p>Other life events in the way.</p> <p>Fluctuating engagement.</p> <p>Avoiding too cumbersome.</p> <p>Stress reducing headspace to engage.</p> <p>Accepting gaps in engagement.</p> <p>Balancing parenting commitments and child struggles.</p> | <p>Parental Mental Health.</p> <p>Challenges in Parenting.</p> <p>Engagement Dynamics.</p> <p>Parental Constraints.</p> <p>Accessibility Considerations</p> |

## Appendix W

### Example Grouping for Key Concept

| Key Concepts                           | SOCIAL CONTEXT OF PARENTS                                      |                                                                   |                                                       |                                                                                  |                                                                  |                                                                                        |                                                                                      |                                                                 |                                                                  |                                                    |
|----------------------------------------|----------------------------------------------------------------|-------------------------------------------------------------------|-------------------------------------------------------|----------------------------------------------------------------------------------|------------------------------------------------------------------|----------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|-----------------------------------------------------------------|------------------------------------------------------------------|----------------------------------------------------|
|                                        | Role as a parent                                               |                                                                   |                                                       | Parental Mental Health                                                           |                                                                  |                                                                                        | Services around the parent                                                           |                                                                 |                                                                  |                                                    |
| Proposed final Theme                   | Parental Constraints                                           | Challenges in Parenting                                           | Recipient Concerns/Priorities                         | Parental Mental Health                                                           | Negative Self-Evaluation                                         | Trauma in parents                                                                      | Bureaucracy in services                                                              | Gaps in Services                                                | Potential Value in Services                                      | Diagnosis as Gateway to Support                    |
| Initial Categories from chart          | Parents have no time or energy (FG1)                           | Supporting child's needs (FG1)                                    | Prioritising child's needs over self (FG1)            | Parental mental health state (FG1)                                               | Felt guilty about child being 'not normal' (FG1)                 | Felt triggered, reminded of past adverse event (FG2)                                   | Being offered multiple tickbox exercises, is this another one? (FG1)                 | Lack of interventions focusing on PAC's experience (FG3)        | Imagining offer as waitlist intervention (FG3)                   | A long process to get a diagnosis (FG1)            |
| Elements/Dimensions Defined from chart | Childcare commitments preventing engagement out of house (FG1) | Unplanned events impact the routine (FG1)                         | Wanting answers/fix to help my situation (FG1)        | Being in survival mode (FG1)                                                     | 'Worries about ability to engage in imagery (FG1)                | Previous adverse events (FG3)                                                          | Interested to use as long as this isn't sold as a replacement to other support (FG2) | Nice if intervention available pre-diagnosis (FG3)              | Opportunity for flexible and multiple uses within services (FG3) | No diagnosis = barrier to receiving support (FG1)  |
|                                        | Lack of time to digest resource (FG1)                          | Unexpected chaos will distract engagement (FG2)                   | How will this intervention help my child? (FG1)       | Little and often practices would feel less overwhelming (FG2)                    | 'Worries about failing as a parent (FG1)                         | Feeling 'triggered' by experiencing compassion (FG3)                                   | Considerations around signposting as most services are localised (FG3)               | Lack of post-diagnostic support services (FG1)                  | Possibility of reducing service burden (FG3)                     | Feeling that doors are closed post-diagnosis (FG1) |
|                                        | Other life events get in the way (FG3)                         | Balancing parenting commitments with child's struggles (FG3)      | Off-putting messages second-guessing difficulty (FG2) | Stress reducing headspace to engage (FG3)                                        | Feeling like "I can't even do that either" re intervention (FG1) | Prevalence of trauma in parents (FG3)                                                  |                                                                                      | We need help, not self help (FG1)                               | Encouraging ongoing evaluation by clinicians (FG3)               |                                                    |
|                                        | Accepting flexible lifestyle (FG1)                             | Experiencing lots of processes in parenting - 'where am I?' (FG1) | Prioritising others over self (FG2)                   | Reaching crisis by assessment time (FG1)                                         | Feeling like a failure (FG1)                                     | Previous interpersonal trauma, questioning 'why was no one compassionate to me?' (FG3) |                                                                                      | Lack of commissioning for parent work that's often needed (FG3) | Huge scope for implications (FG3)                                |                                                    |
|                                        | Having different scenarios and amount of spare time (FG1)      | Going through trials and tribulations (FG1)                       |                                                       | High parental mental health rates (FG3)                                          | Blaming self for everything (FG2)                                |                                                                                        |                                                                                      | Unsure what other interventions exist (FG3)                     | Prompting writers to consider licensing (FG3)                    |                                                    |
|                                        | Wanting to engage in something whilst doing other things (FG1) | Hell and back before anyone would refer (FG1)                     |                                                       | Burnout and lack of compassion effects ability to use parenting strategies (FG3) | Feeling like a failure if not followed workbook timeline (FG2)   |                                                                                        |                                                                                      | Lack of experiential parent support (FG3)                       | Value as a flexible tool (FG3)                                   |                                                    |
|                                        | Doing as a family activity to save time (FG1)                  | Waiting for child's support (FG1)                                 |                                                       | A pathology could exist and hasn't met a service criteria (FG3)                  | Wondering if doing exercises right (FG2)                         |                                                                                        |                                                                                      | Acknowledging gaps between health service criteria (FG3)        | Enjoyed reading it (FG3)                                         |                                                    |
|                                        | Options to meet time and headspace (FG3)                       | Child's mental health concerns (FG1)                              |                                                       | Often seeing referrals because parents are overwhelmed (FG3)                     |                                                                  |                                                                                        |                                                                                      | Less variety of models to offer in children's services (FG3)    |                                                                  |                                                    |

Appendix X

Final Compassionate Mind Training for Parents of Autistic Children (CMT-PAC)  
Resource

DRAFT 5:

# Compassionate Mind Training for Parents of Autistic Children

Written by: Fran Kemp

*Are you the parent of an autistic child?*

*Do you find you're your own worst critic?*

*Spent ages feeling you're not parenting the 'right' way?*

*Then this workbook could be helpful for you!*

**Acknowledgements:**

Many thanks to all the parents, clinical psychologists and compassion focused therapy clinicians who have contributed to the development of this workbook.

A big thanks to Dr James Kirby of the Compassionate Mind Research Group for sending through his initial resource with kind permission to adapt it into this workbook.

Thank you to Andrea Kocurkova for kindly providing the drawings used in page 16 of the workbook!

Finally, thanks to the research team for supervising and supporting the adaptation process: Dr Mark Hudson and Prof. Thomas Schröder of University of Nottingham, and Dr Corinne Gale from an NHS Trust.

This workbook includes colour-coded text boxes for ease of access. The following key is provided to share the purpose of each type of text box.

**Textbox Key:**

**Red** = Key points from the chapter (bitesize summary).

**Amber** = Top tips.

**Blue** = Space to write any thoughts.

**Green** = Time for practice (check audio tracks).

**Purple** = Examples.

**A note about language use:**

We have looked at the current research to find out the preferred way of describing autism. Currently, identity-first language (words like 'autistic') is most favoured by autistic people across the globe. Therefore, we have used this term throughout this workbook. However, we recognise that people use many different words to talk about neurodiversity.

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### **A bit about this book...**

Welcome to this Compassion Training workbook. For the next few weeks, you can use this resource to develop and direct compassion towards yourself and others.

Research shows that compassion can increase parents' quality of life and help to reduce problems like stress, anxiety, depression, shame, and self-criticism, which are often experienced by those navigating through the unique differences and challenges of parenting an autistic child. Therefore, we hope that by completing this workbook, both yourself and your child can experience the benefits of this practice in your daily life.

This booklet was developed by a research team of Clinical Psychologists at the University of Nottingham and through consultation with parents of autistic children, Clinical Psychologists who frequently work with such parents and who are trained in Compassion Focused Therapy.

### **Who is this for?**

This workbook was made for parents of autistic children at any age. However, the ideas and techniques in this workbook can be useful for parents of children with suspected autism or autistic traits, regardless of whether your child has received an autism diagnosis or not.

This booklet is aimed at parents who experience stress and want to enhance their wellbeing. This workbook is not designed to work as a crisis intervention and should not be viewed as a replacement to a parent's access to in-person mental health support if required. Therefore, should you currently be experiencing severe distress, including thoughts of self-harm or suicide, we would not recommend this workbook and would advise that you contact your GP to seek support from mental health services.

### **What will it cover?**

This workbook is split up into six parts, with each section involving some reading and some practical exercises to try.

- In the first part, you will learn about the importance of compassion and how this can improve your wellbeing.
- In the second part, you will think about how this relates to being a parent of an autistic child.
- In the third part, we talk through some top tips as you prepare to develop your compassionate self.
- In the fourth part, you'll practice using compassion towards others.
- In the fifth part, you'll experience directing compassion towards yourself.
- Finally, in the sixth part you will think about how you can take the learning about your compassionate self forward through the journey of parenthood.

### How often should I use this resource?

We recommend that you try to read one chapter each week and practice the associated exercises for that chapter at least once a day. On average, this should take you no longer than 10-15 minutes daily. Each audio track exercises have written scripts attached to the end of each chapter just in case you'd like to read it through. You don't need to read this as you listen to the audio track unless you'd like to.

We have put a suggested timetable below. However, we recognise that sometimes it might not always be possible to set aside some time for reading, whilst you manage the demands of being a parent. If you needed to miss some time – this is understandable. You can always come back to this resource when you can.

| Week | Reading                                                                 | Exercises                                                                                                                                                                                      |
|------|-------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1    | The experience of parenting (7 pages)                                   | Audio Track 1: Posture (5 minutes daily)<br>Audio Track 2: Facial expression (5 minutes daily)                                                                                                 |
| 2    | Working with our tricky brains (9 pages)                                | Audio Track 3: Soothing Rhythm Breathing (5 minutes daily)<br>Audio Track 4: Mindfulness: (10 minutes daily)                                                                                   |
| 3    | Developing your compassionate self with practical guidance (6 pages)    | Audio Track 5: Developing your compassionate self (10 minutes daily) OR<br>Audio Track 6: Developing your compassionate self – extended version (15 minutes daily)                             |
| 4    | Directing compassion towards others (3 pages)                           | Audio Track 7: Directing compassion to others (10 minutes daily)                                                                                                                               |
| 5    | Directing compassion towards yourself (3 pages)                         | Audio Track 8: Directing compassion to the self (10 minutes daily)                                                                                                                             |
| 6    | Taking the compassionate self along the journey of parenthood (4 pages) | Compassionate Letter Writing (written exercise).<br>Compassionate Object exercises (optional)<br><i>(You are welcome to continue use any of above audio tracks as often as you would like)</i> |

### What's the result for me?

We hope that Compassionate Mind Training can support you to develop your own compassionate self, which you can choose to take along with you through your journey of parenthood and the rest of your life experiences.

However, it is important to note that this is a brief workbook, and getting used to using your compassionate mind takes lots of practice. Therefore, we would view this self-help course as being the start of a much longer journey of developing a compassionate self, but we hope that you will start to experience the benefits of this over the next few weeks.



Here are two parents who we can refer to as you use this workbook. Let's introduce you to Stacey and Ryan:



Stacey is a single 33-year-old mum to two boys, ages 3 and 12. She enjoys reading and playing fantasy board games, and she aspires to write a fantasy novel one day. She used to work in retail but found managing the customer interactions too tricky. She has been in and out of work for a few years but has recently started a part-time office job.

Stacey's eldest son was diagnosed after an autism assessment two years ago. Since then, Stacey herself has realised that she is autistic too. She related to many of the things that her son shared in his assessment. Stacey can find certain lights and sounds to be too much, and she finds it harder to 'tune in' to how her body feels. She likes order and routine and can feel overwhelmed when things go wrong. Sometimes she finds it hard to read facial expressions too.

Apart from the school run and to go to work, Stacey doesn't go out often with her children. In the past, people have occasionally rolled their eyes or whispered whilst she is trying to support her son when he is becoming overwhelmed. She just wants to get parenting 'right' and often criticises or blames herself when it all feels like it's going wrong.

Ryan is 27. He recently married his husband Olek, and they have an adoptive daughter, aged 6. Ryan studied media production at university and has just got his dream job in TV, but this means he often works away for weeks at a time.

Olek has shared worries about their daughter's development for years now. She doesn't seem to be meeting the milestones that are written in all the parenting books that they had read together. They have gone to their GP over and over for years to ask for an assessment. Frustratingly, the GP has only just finally agreed to send a referral, as their daughter is otherwise doing well, and her primary school teacher has no concerns.

Ryan often feels guilty when he must go on work trips, as he doesn't like to leave Olek to manage everything at home. However, Ryan feels even worse about himself when he comes home, and their daughter doesn't look at him or want to play with him. Ryan often thinks that he is a rubbish Dad, and a rubbish husband too. He tries to make the most of the time that he's back by taking them on family days out, but sometimes their daughter gets really upset in new places. This makes Ryan feel even worse – like he doesn't understand his own daughter.



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7

## WEEK 1

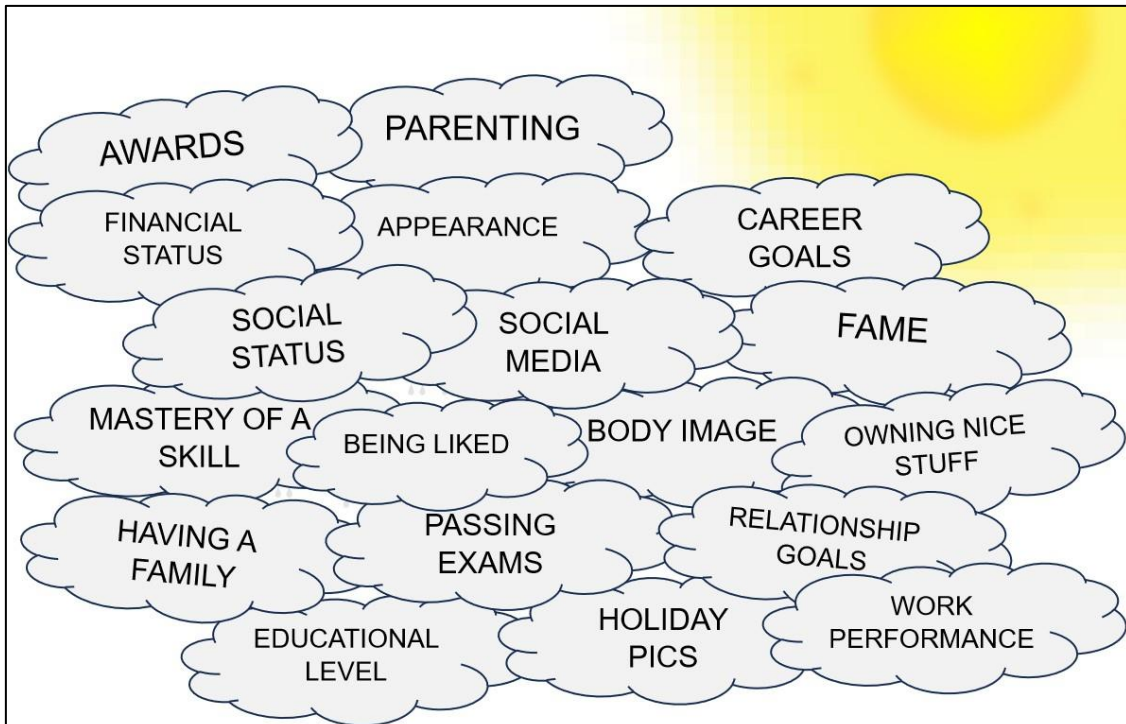
### The Experience of Parenting

#### **Chapter Aims:**

- To understand some of the challenges to we face in parenthood.
- To think about how compassion might help us.
- To introduce some exercises to try over the next week.

#### **What's the reason for this chapter?**

Before we begin, it's important to start by thinking about some of the things that we might experience in life – particularly through parenthood! By noticing that all of us will go through times where we're suffering, we can start to think about some of the challenges we might face when practicing developing and directing compassion towards ourselves and others.



***“You are your own worst critic”.***

Most of us can be very hard on ourselves, and a lot of us can find it difficult (or nearly impossible) to treat ourselves with care and kindness. We might become so focused on what we want to do next, or do better, rather than thinking about how we are, right now, in the present. Often, we aren't aware of how this clouds our thinking, our feelings, and our judgements.

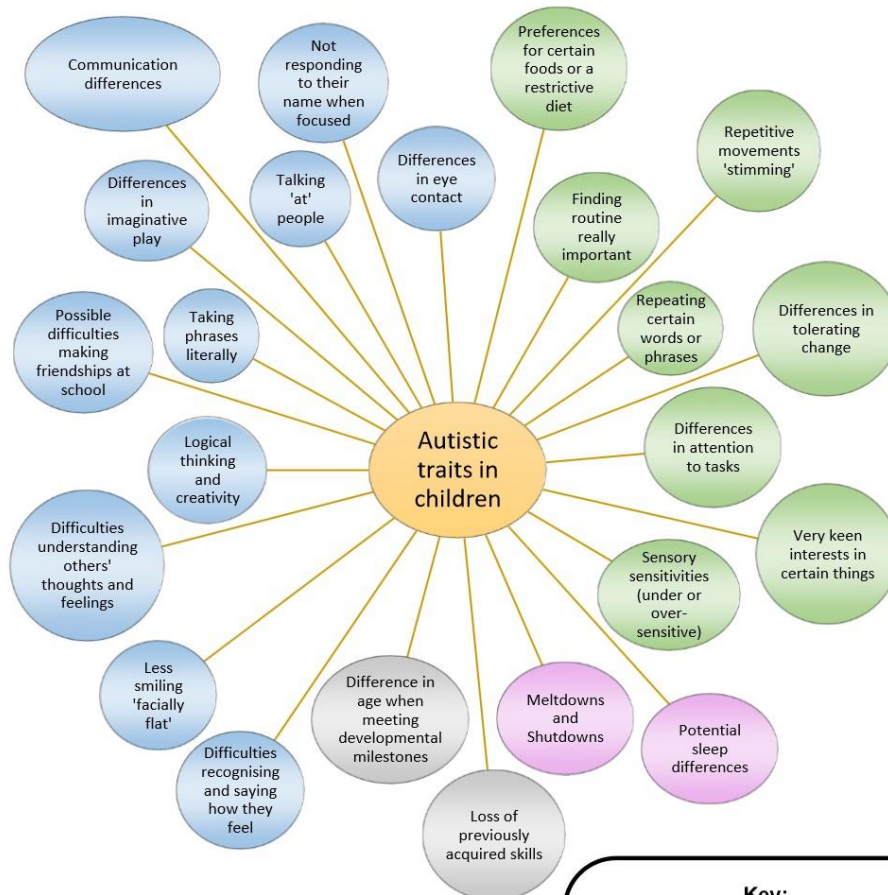
Modern society often focuses on achievement, whether that's our appearance, social status, career, education, financial status, and so on. We experience excitement or pleasure from meeting a target or passing a test. However, we can easily feel threatened, should we experience any barriers to achievement, or if we don't 'match up' with others we compare ourselves to, like famous people or a friend posting an achievement on social media.

We are all prone to thinking in such ways, which can cause us to experience a real range of emotions, such as joy for our own goals, or fear of our own failure, or anger towards perceived injustice, or shame about our own experiences.

How does this relate to your experience of being a parent?

**Now let's think about some of the common traits we see in autistic children:**

*(You might already know these, but some could be new to you).*



This list is by no means exhaustive. Autistic traits are so varied, and every single autistic person has their own list of strengths and difficulties.

Let's think about some of the unique challenges that parents of autistic children might have, in respect to some of the above differences identified. Again, some of these might feel relatable to you, and others not. Either way, that's okay!

**Key:**

- Blue** = Social interaction and communication differences.
- Green** = Restricted or repetitive interests, activities, and behaviours.
- Grey** = Developmental differences.
- Pink** = Potential impacts from autistic differences.

### **Challenges we face as parents.**

Being a parent for many is extremely rewarding and greatly valued. However, research has found that our happiness tends to drop slightly after we become a parent. This is important, as we often think parenting should be full of happiness and joy. But it makes a lot of sense, as when we become parents, lots of sacrifices are made, we lose lots of sleep, and we can experience lots of guilt. We may also worry much of the time about whether we are doing things 'right'.

When parenting an autistic child, all these points might happen more often, as suddenly we find ourselves noticing our child might not be developing in the way that the books tell us they should be. We might be needing to manage different sorts of behaviour, and wondering why our child is different to others. Some of these behaviours, like meltdowns, can be particularly challenging to manage, and distressing for all involved. Maybe some of us start to question "is this my fault?" (*The answer to this is most likely no*). Many of us might have heard of labels like autism, but our understanding of what this means might be vague.

Nevertheless, we might start to talk about what we've noticed to our friends, our family, our partner, the nurse, the GP, the teachers. Some of us might quickly move forward to being placed onto a waiting list for an assessment, but others might face delays and feel that we must push for our child to be seen. We must fulfil many different roles for our child: the parent, the advocate, the teacher, the behaviour analyst. All whilst coming to terms with our new identity as a parent and the changes to our sleep and routine that may follow.

With all the above in mind, perhaps it is not surprising that research is showing us that parents of autistic children are at risk of higher amounts of stress, anxiety and low mood compared to other parents. We have not chosen this journey, but we find ourselves here, doing the best we can for our child despite the challenges we are up against at times.

### **Managing judgement within a 'neurotypical' world.**

All parents can feel incredibly judged at times, whether meeting friends, or talking to school, talking to services... even when seeing a stranger on the street whilst we're managing a meltdown. When we feel judged like this, it can make us stressed and often all we want to do is hide, escape, or run away. Some people who feel judged might get angry.

Some of us deal with judgement by trying to make sure we are the 'perfect' parent, so that we can only be judged positively or favourably. So as parents, we can easily shift into a competitive mind-set, because we want to be the 'best parents' we can be, and we don't want to make any mistakes, as that can lead to judgment. That of course means we are constantly monitoring ourselves and what we do as a parent, we compare ourselves to other parents – am I better or worse than other parents – and this kind of thinking can make us vulnerable to self-criticism, depression, and anxiety.

Some of us may fear judgement from others so much that we avoid situations where we might be judged. We might put off going outside with our child or avoid meet-ups with friends or other parents, who we fear won't understand what it's like to parent an autistic child. Of course, a consequence of avoiding getting out and seeing people is that many of us can start to feel lonely – and again, this can make us vulnerable to other mental health difficulties.

### **What compassion is...**

Compassion has two main parts: 1. being aware of the possible suffering in us and others, and 2. being ready to do something about it, to prevent it from happening or to make things a little easier if it's already happened. Researchers suggest that compassion is built up from six different qualities:

1. **Wisdom:** Learning from our own personal experiences as we go through life.
2. **Maturity and Insight:** Knowing that highs and lows are a very normal part of being human.
3. **Strength:** Being able to stand up for ourselves and shield against suffering if needed, but also learning how to tough it out and tolerate this suffering sometimes too.
4. **Warmth and Kindness:** We're understanding and here to support each other so that we can all feel better about ourselves.
5. **Non-judgemental and Non-condemning:** We don't judge or 'hate on' stuff. We just keep an open mind and see situations for what they are.
6. **Sense of Responsibility:** A strong urge to make a difference and help others in a good way.

#### **Example:**

Ryan saw his daughter pulling at a shelf. This was making a heavy box at the top begin to wobble. It looked like it might fall onto her.

Ryan quickly shouted STOP and ran over to move her away. This put him in danger of the falling box too, but he did it to protect his daughter anyway.

This was a compassionate way of responding: he saw she might potentially suffer, so he took action to prevent this.



### **What compassion isn't...**

Some people think that compassion is all about just being kind or is seen as 'soft' or 'weak', or even a bit indulgent. But compassion helps us gather the courage to face the challenges in our lives.

Compassion isn't a sign of weakness; in fact, it can truly help us when times get hard. Compassion helps us to understand, recognise and face difficulties with great strength and resilience.

### **How might compassion help?**

You might have noticed that the qualities of compassion are also key parts of parenting – we are sensitive to our child's needs, and we work to try and meet these to help our child to be happy.

Children need us to help co-regulate their emotions, as well as explore the world. This can help to develop an emotionally secure relationship with our child. However, autism can make parenting more challenging, as it might be harder to us recognise our child's needs, and harder for our child to communicate their needs. As parents, we are going to make mistakes or miss things sometimes. **This is nobody's fault**; it is just part of being a human. But when we make mistakes, how do we relate to ourselves? Is it with a competitive mind-set, one which is quick to attack and criticise? Or are we able to activate our compassionate mind-set? One which understands the struggle and wants to encourage us to keep trying because it is important to us.

We can also put a lot of pressure on ourselves. Many of us want our children to flourish and lead as full a life as possible. This can sometimes lead us to having expectations that our children should be able to do 'more' than they are currently able to developmentally. When children act, behave or do things that we think they should be able to control, that can make us – as parents – feel bad. If others are then around to witness what happened, that can make us again feel judged. Compassion can help us to accept our child as they are and reduce this pressure on ourselves.

So being a parent is tricky, particularly if we have unrealistic expectations for ourselves and our children. The key is to not try and think of 'right' or 'wrong', as this is linked to our critical self. Rather, try to playfully work out what strategies might work or be helpful. Knowing that mistakes will happen, and that is okay. We learn from making mistakes, and so do our children.

**If our children can see us being compassionate to ourselves in times of stress, hopefully they will start to imitate that as well.**



### **What next?**

Now, you might be wondering “Okay, I’ve recognised how I’m feeling, and I am hearing that compassion can help me... but what am I supposed to do next?”. For this week, the following exercises work to create the conditions in your body and mind to channel compassion. Try to have a go at doing these daily if you can.

The next chapter will talk about how our minds have evolved over time, and why we have all these different emotions, passions, and desires. Understanding this is super important, because it helps us realise that we don’t consciously choose to have these experiences. Once we see this, we can better understand the challenges we face.

### **Key points from this chapter:**

- Life, including parenthood, can certainly be rewarding. However, it involves lots of tricky challenges to manage, which can leave us vulnerable to problems like stress, anxiety, and low mood.
- There are some particularly tricky differences that parents of autistic children may manage, which can all impact on parent’s mental health.
- Knowledge of our position in the world as a parent, our situations and how we might respond to them is a great first step. That way, we can then start to notice and choose when we might like to bring compassion into our lives, to direct it towards ourselves and others.

### Time for Practice

To help access a compassionate mind state, it's very useful to work with our bodies and breathing. So, these next two exercises will help you to create conditions in your body and mind for compassion development. Try to practice both exercises daily.

#### Before we get started...

Many of these exercises might be new to you. If you notice that you're finding it hard, that is okay. It doesn't mean that you're doing it wrong, or that it can't work for you. If you're finding it hard, I'd recommend that you read chapter three – it has some top tips that can be relevant to all exercises.

Some of us might find it tricky to focus our attention on our bodies and facial expressions. There are some things that you could try. This is what Stacey did:



Stacey finds it tricky to tune into how her body feels. These are things that seemed to help:

- Setting a timer in the morning to remind her to spend five minutes focusing on the sensations in her body.
- Holding a warm item and practicing bringing her awareness to the sensations that the temperature creates:
  - What does it feel like? Where does she feel it? Does it feel nice, neutral, or unpleasant?
  - Then she put the item down and checked in again: how does the sensation change?
- Similarly, she gently stretched a muscle for a few seconds and focused on the sensation that this creates. After a few seconds, she relaxes the muscle and notices how the sensation changes.
- She practiced her posture changes in the mirror, whilst listening to the audio track and looking at the example picture over the page.

Some of us might also have physical differences that we need to think about too. You might be experiencing pain or injuries affecting your back, ribs, or shoulders. You may have conditions affecting your breathing, like asthma or COPD.

**If there are any possible reasons why practicing changes to your posture or breathing could cause a problem with your physical health, please speak to your doctor to check that each of these exercises are safe to try before having a go.**

### Creating a base for compassion training (Audio Track 1)

We can use our bodies to create states that will help us access our compassionate state. We can begin by paying attention to our posture which supports a particular style of breathing and a sense of grounding in the body. So, let's focus on posture. We will do this exercise sitting down.

To begin this exercise, sit in a comfortable chair that allows you to sit with your back upright and your shoulders slightly back. Notice that if you are sitting at the computer or at a desk, we often tend to curl our shoulders in and close the chest like this:



So, for this exercise, we are going to sit up straight, lift our shoulders up and backwards, notice how that opens the chest for breathing. You might practice that movement.

When we are slightly threatened or anxious, our shoulders tend to curl inwards. This crunches up our stomach and chest. So, we deliberately open the shoulders and chest for this breathing exercise. Notice too that when you do this, your back goes from a hunched over shape to a straighter shape, like this:



*Head straight.*

*Move  
shoulders back  
to open chest.*

### Script for Audio Track 1



*Place your feet firmly on the ground, shoulders width apart.*

*Your shoulders should be more or less in line with your hips and ears over the shoulders.*

*Try to sit away from the back of the chair so you can keep your back straight.*

*This is a body posture which is to create stability for us. It is, in a way, the posture of confidence and authority.*

*It is important to find a posture that is comfortable and that helps you be in a state of alertness and vigilance, but at the same time don't let your muscles become too relaxed. Try to adopt a posture that helps you to keep your back straight, aligned, but not rigid.*

*Noting the natural curve of your back, with your ears in line with your shoulders.*

*Let the body relax. However, this is not letting the muscles become floppy, like for sleep, but more like imagining a diver on a diving board preparing to take the dive. The body is relaxed but not floppy, and it's preparing for concentrated attention and action.*

*You can close your eyes or keep them softly open, looking down to the floor. If you find yourself becoming sleepy at any point in the exercises, just let your eyes open a little.*

*You can rest your hands softly on your lap.*

*So, you are creating a posture of alertness and serenity, with an internal sensation of stability. A stable and calm posture, just like a diver that walks to the edge of the platform and calms him/herself down by creating a point of stability.*

*This position and posture also convey strength and authority. While you are sitting doing the exercises, see if you can feel like a mountain – equally solid and strong.*

*With this posture we can calm our mind and prepare it to the practices that follow.*

**You can make notes here immediately after your practice, to remember anything that you noticed as you were trying exercise one.**

An example topic is in the box, but you can choose your own.

**What changes did you notice in your body after focusing on your posture?**

### Using facial expression and voice tones (Audio Track 2)

There are other ways that we can use our mind to change our body. Method actors, for example, know that the way we use our voice tones and facial expressions has a great impact on our body. Good actors can deliberately create emotions within themselves by using voice tones and facial expressions. In this exercise, we will begin by exploring the difference between a neutral facial expression and a friendly facial expression. The idea is that you simply notice what happens when you deliberately change your facial expression between these two states.

We are also going to look at the power of the emotional textures of our thoughts. It's not just what we think, but how we think too. The tone of our thoughts can vary. They might be harshly critical, or excited, or supportive and understanding. Just like the voice tones people use when they talk to you can have a big impact on us, so can the emotional tones of your thoughts can have an impact on you. Often, we are not aware of the emotional tone of our thoughts but if our thoughts have a hostile tone, this will have an impact in our body. When we're practicing developing our compassionate state, it's important to pay attention to the tone we use and stimulate an internal voice tone that is compassionate and friendly. Let's do an exercise to explore this now.



*To explore how powerful facial expressions and voice tones can be you will first sit in a stable and alert position and gently closing your eyes and feel comfortable. Once again, hold the posture you have been practising and let your body relax.*

*During this exercise, you will keep a neutral facial expression for a few seconds, then you will switch to a gentle smile and friendly facial expression.*

*Imagine you are with a friend that you care about and that feeling of friendship and kindness towards them is expressed through your face, so you are also trying to create a feeling in your facial expression.*

*As you repeat this exercise, just try to notice how creating these facial expressions can change your feelings even subtly.*

*Begin by creating a neutral facial expression and try to keep it for about 20 seconds.*

*Now try to create a friendly facial expression. Hold this for about 20 seconds.*

*Now again try to create a neutral facial expression. Hold this for about 20 seconds.*

*Finally, create again a friendly facial expression. Hold this for about 20 seconds.*

*Reflect for a moment how this experience was for you. Notice how you felt in each situation. Of course, you can think this is an artificial situation, but that is not the point here. **(Continued overleaf)***

*The important thing is to notice how we can stimulate certain mental states by creating different facial expressions.*

*We are now going to say hello to ourselves on the outbreath. This means naming yourself. So, first on each outbreath just with a neutral voice tone say hello to yourself, naming yourself. So, if your name is Jayne or Jon, it would be hello Jayne or hello Jon.*

*We will then contrast that with a friendly tone and again the idea is to create a voice tone; imagine your greeting somebody you really like and are pleased to see really try and create that feeling in your voice tone.*

*So, when we do the exercise, we are going to combine facial expression and voice tones.*

*We start with neutral, creating a neutral facial expression and a neutral voice tone saying hello to yourself. When we switch to friendly, create that friendly face expression again with the feeling in the face and also the friendly voice tone as you greet yourself.*

*So, let's start then first 20 seconds of neutral face and neutral voice tone saying hello to yourself.*

*Now try using a friendly facial expression and friendly voice tone for 20 seconds.*

*Now back to neutral facial expression and neutral voice greeting for 20 seconds.*

*And now one more time, let's go back to a friendly facial expression and voice tone for 20 seconds.*

*So, during this exercise you might have noticed that practicing creating a friendly facial expression and voice tone can stimulate these feelings in you. It can be useful in some of the practices to try to adopt a friendly facial expression and voice tone. Now when you are ready open your eyes or refocus and look around you, and take a stretch, moving your body.*

**Top Tip for all exercises:**

Worried that you may struggle to find the time to try out the daily exercises at the end of each chapter? Maybe you're a bit unsure about how you'll fit this around parenting responsibilities?

If you have an older child and you think that they'll likely understand and follow the audio tracks, why not try practicing the exercises at the end of each chapter together!

You can make notes here immediately after your practice, to remember anything that you noticed as you were trying exercise two.

Write any thoughts here:



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## **WEEK 2**

### **Working with our Tricky Brains**

#### **Chapter Aims:**

- To understand what we mean by compassion.
- To introduce the idea of having a tricky brain.
- To understand our different types of emotions.
- To introduce some exercises to try.

#### **What's the reason for this chapter?**

This chapter aims to introduce you to Compassionate Mind Training, to help you think about how compassion can influence your emotions and support you to lead a more fulfilling life. The first step to being able to develop your compassionate self is to understand what that means for you and how it is likely to work.

The practices this week are there to help you to start on your journey of developing a compassionate self, by getting used to taking a few minutes out of your day to self-soothe, whenever you can.

**You've picked up the book! Welcome back.**

**What happens in the brain when we're suffering?**

The short answer is a lot - our brains can be tricky. The human brain allows us to do some wonderful things, but it isn't well designed, and at times can lead to ways of behaving that we don't intend.

**This is no one's fault.** It is just way the brain has evolved.

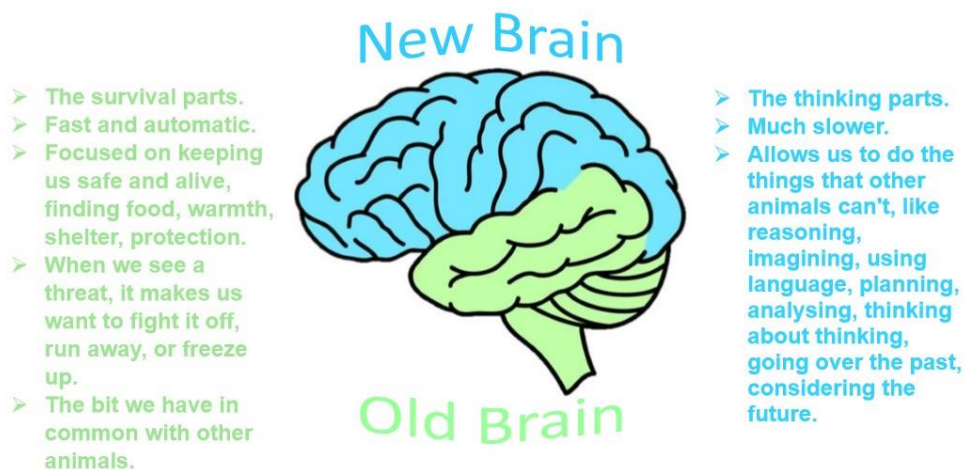
Our brains are shaped by our genetics and experiences, so we're all unique. However, the basic structure of our brains is generally similar.

**Quick note:**

The section uses ideas from the theory of human evolution.

If you aren't comfortable with this theory, just pay attention to the parts about how the different parts of the brain work together.

We can think about our brains as having two main parts:



Although both parts of the brain can be immensely helpful, sometimes the way they work together can cause us a lot of suffering, because we can hold things in mind that can make us feel painful emotions like guilt, shame, anger, fear or sadness.

Let's look at how our tricky brain differs to other animals' brains over the page.

### **What happens in animal's brains?**

Other animals have 'old brain' bits like us, but they don't have the new brain bits. So, they respond pretty much like us when they sense danger.

Imagine an antelope grazing near a watering hole. Suddenly, it sees a rather hungry looking lion. The antelope's old brain senses danger.

The antelope's survival instinct kicks in, and it automatically starts to run away as fast as it can.

Once it reaches safety, the antelope quickly calms and goes back to eating.

### **What happens in our human brains?**

Now, we have both the 'old brain' and the 'new brain' bits. As the picture on the last page showed, this gives us loads of skills which can be really useful in our daily lives. But let's think about what happens when we are suffering, using the same example as above.

So, initially when we sense danger, we respond exactly as animals do. If a lion walked into the room right now, I bet some of us might try to run away, some of us might freeze up, and maybe some of us might even try to shout or fight it to make it go away. That's our old brains at work, exactly like the antelope's above.

However, it is after the event where us humans differ to other animals. Once the lion has gone, our new brain comes online. We might start to think about what happened over and over again (*it had such massive teeth!*), or think about the worst possible scenario (*what if I had become it's lunch?!), or start to worry about the impact on the future (who would have looked after my child then?!). These are all really normal responses to a scary situation, and the new brain is actually trying to help here. It's trying to work out what happened, so we can plan ahead to try and prevent it from happening again.*

However, as we hold this stressful memory in mind, it can cause us lots of uncomfortable feelings (probably fear here). These feelings can actually bring the old brain back online; we feel scared, so the old brain thinks "we must be unsafe!" and gets ready to protect us again.

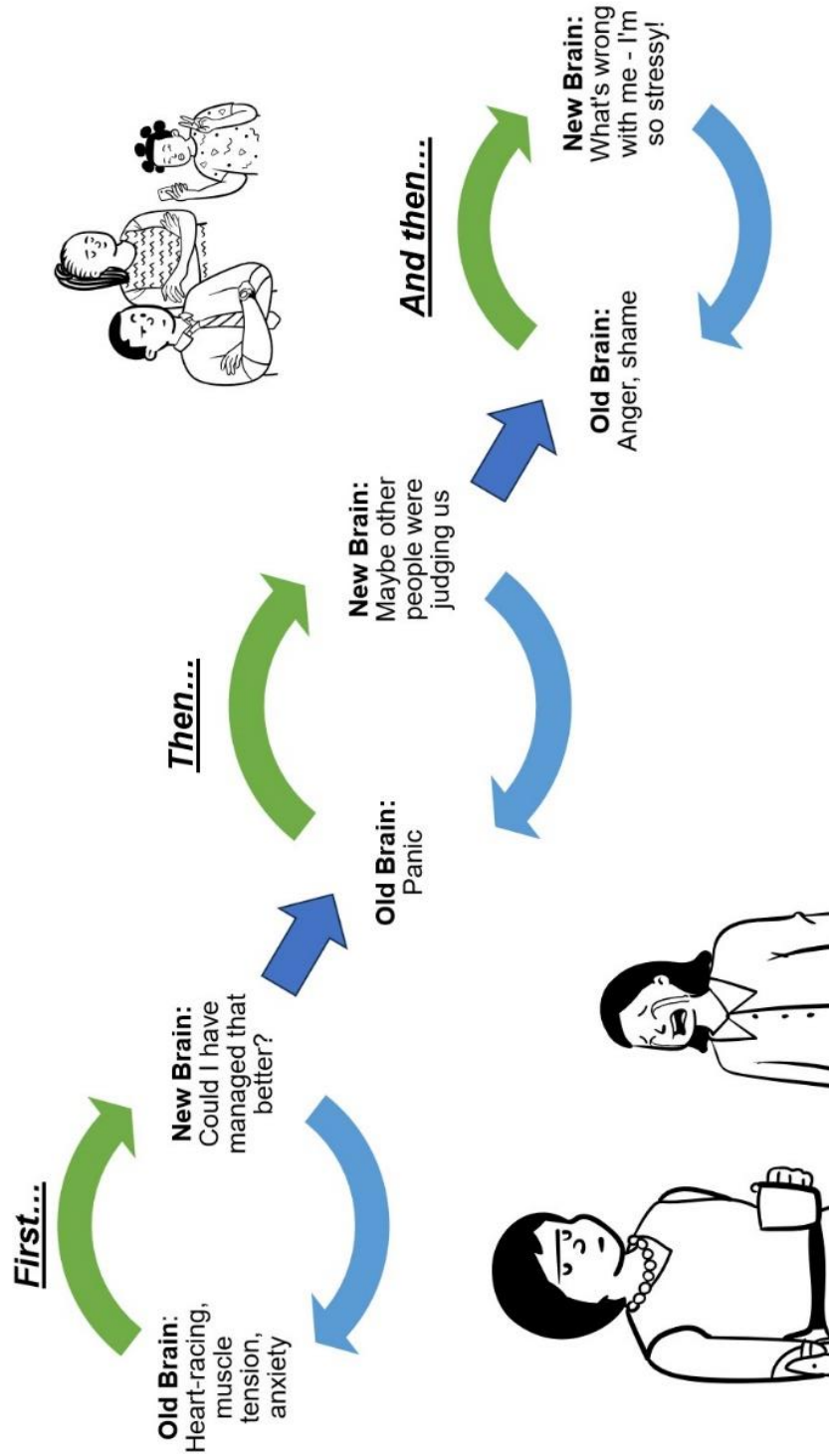
This is one example of how we can end up stuck in unhelpful 'thinking loops' between the old and new brain. By keeping these types of thoughts in our minds, we can end up in constant loops of stress and worry.

### **Remember: this is not our fault.**

It's just the way the mind is, unless we learn to notice what it's up to and shift our attention.

Let's look at an example of our old brain and new brain getting into an unhelpful thinking loop.

Stacey had to pick up her son from school to take him to a doctor's appointment. He became really upset as this was an unexpected change to his day. Stacey supported him as best she could but worried that people were judging them both. This made her feel under threat, so her old brain came online and...



## Our Emotion Systems

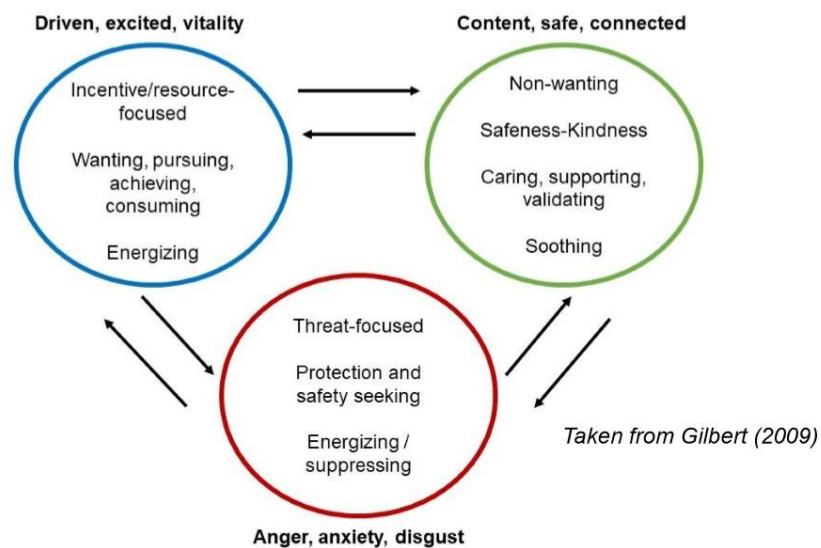
Developing compassion includes understanding and working with our emotions. The human brain has been evolving over many millions of years. This is why we share basic motivations with many other animals. They, like us, are motivated to find food, avoid harm and dangers, live with others in groups, form relationships, seek out sexual opportunities, and look after their offspring. To help us with these life tasks, we have evolved different types of emotions.

There are at least three types of emotion systems that are useful to know about. These emotions help us with three important things in life:

### 1. Dealing with threats

### 2. Being driven to want and achieve things

### 3. Contentment and soothing

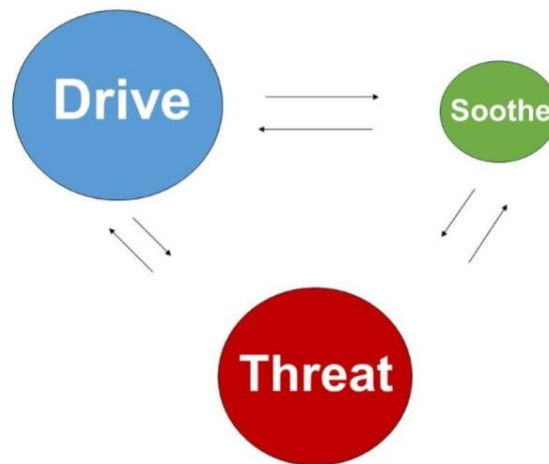


Each of these emotion systems have a purpose. The **threat system** activates us by directing our attention and thinking to a possible danger, to find ways to protect us and keep us alive. The **drive system** helps us to seek out good things, like food, excitement, achievement and owning things. The **soothing system** helps us to calm and slow our bodies down, to become more peaceful and rested. It is important to recognize that this system is also very important in caring behaviours. The reason for this is that caring behaviour to others also helps us to feel calmer and more at peace within ourselves.

Depending on our past experiences, we might have needed to use certain systems more often than others. This makes them more familiar to us and more developed, which might increase how easily they are activated in the future. If we think about visualising this idea through having different 'sized' systems, some people who have experienced repeated threatening situations, might have emotion systems which look like this:



And someone who has needed to seek a sense of achievement in order to cope, might have emotion systems which look like this:



In both of these examples, we can see that the person's soothing system is not as well developed, and the three systems are not in balance.

### **We have different mini-selves within us**

Given then that we have these different motives and drives, and associated with these we have many different types of emotions, you won't be surprised to hear that our minds are complex. We have all kinds of mini-selves such as 'sad self', 'happy self', 'critical self', 'ashamed self', 'guilty self', 'perfectionist itself' and so on. As each self 'takes the stage', it makes our brain go into different patterns of thinking, feeling, acting, and remembering. So the question is: can we start to choose a pattern and type of self that actually brings harmony to our bodies, minds and relationships?

Well indeed we can, and this is called the Compassionate Self. So like any other aspect of self, it has its own way of thinking, feeling, acting, and memories. But how can we put the Compassionate Self in the spotlight?

### **The power of attention**

Attention is very powerful, because where it settles will have an impact on our bodies and emotions. Therefore, it's quite useful for us to be aware of where our attention is focussed. What you pay attention to becomes bigger in your mind, as if a spotlight has fallen on it. However, other things then go into the shadows, and you become less aware of them. For example, as you focus on your left foot, you are not aware of your other foot.

So, when one mini-self is 'in mind' in the spotlight of our attention, many of our other mini-selves could be out of mind. So while you are caught up in 'angry self' or 'anxious self' or 'worrying self' you may be unaware of all of the potential that sits within compassionate self. Only by noticing it and then directing attention may you be able to switch attention from one mini self to another – no different in principle from switching your attention between your left for your right foot—though our emotions of course make it more difficult.

So in essence, this is what compassion training is about – beginning to notice when we are becoming overly dominated by mini-selves such as the 'angry self', 'anxious self', 'worrying self', 'self-critical self', and making a deliberate choice to switch to our compassionate self. We can deliberately develop this self in our everyday lives, rather than letting 'anxious self' or 'angry self' run the show.

**Example:** *After Stacey returned from the doctor's appointment (see page 26), her 'critical self' had snuck into the spotlight without her noticing, and it was making her feel rubbish!*

*Stacey paused for a few moments and asked herself "which mini-self is in control right now? Are they being helpful?". This focused her attention on how she was thinking and feeling, and she realised that her 'critical self' was in charge. She took a deep breath, paused for a few moments, and thought "how might my 'compassionate self' respond to this right now?"*





### Introducing your critical self

We all have an inner critic. How many times have you heard people say things like "I'm a failure", "I never do anything right". "I should have done better" or "I'm not good enough!".

Critical thinking can cause us to experience changes to our body sensations, feelings, and how we act. For some, it can lead to feeling worthless, guilty, ashamed, or anxious. But how does a critical thinking style differ from a compassionate thinking style? Well, let's look at this:

| Threat-based thinking styles                                                             | Compassionate Thinking styles                                           |
|------------------------------------------------------------------------------------------|-------------------------------------------------------------------------|
| Closely focused on threat                                                                | Broadly thinking and considering lots of different parts to a situation |
| Tries to label things quickly                                                            | Takes time trying to understand                                         |
| Really rigid and overthinking                                                            | More flexible, tries to problem-solve                                   |
| Can make us feel emotions like fear, disgust, shame or anger towards ourselves or others | Can make us feel emotionally safe and connected to ourselves and others |
| Can seem pretty judgemental and critical                                                 | Empathetic and encouraging                                              |
| Focuses on trying to avoid suffering                                                     | Concentrates on understanding suffering and finding ways to reduce it   |

**Exercise:** What things do you usually criticise yourself about?  
What sort of things do you typically say to/about yourself?

I wonder what you noticed about your self-critical thoughts, and how it made you feel. One of the unhelpful consequences of having a frequent self-critic is that this can lead to lots of different mental health problems such as anxiety, stress, depression, low self-esteem, lower quality of life, etc., AND this can also make people feel stuck in their suffering.

Be curious about often your self-critic is present and whether you notice it. These moments can often happen without us really thinking about it, but they are prime opportunities to stand back and decide whether we want to engage with the self-critic, or whether we choose to face this with compassion.

The following chapters in this book can help you to develop your 'compassionate self'. There will be plenty of opportunities to practice bringing your compassionate self to 'take the stage' of your mind. We can do this step-by-step each chapter, or at a pace that works for you. In preparation for this, we advise that you try this week's exercises once daily to practice directing your attention and mindfully engaging with your body. These skills will be helpful to support the rest of the exercises in the programme.

**Key points from this chapter:**

- Compassion helps us to understand, recognise and face difficulties with great strength and resilience. When times are hard, compassion can really help us get through them.
- Our highly developed brains can be tricky and may accidentally keep our stress, worry or anxiety going: **this is not our fault**, it's how our brains are designed.
- Developing our awareness of which emotional system is online can help us to make a deliberate decision to switch from our 'angry self', 'anxious self' or 'critical self' to our 'compassionate self'.
- This week's practices intend to help you start to direct your attention and practice soothing rhythm breathing, as first steps to developing your compassionate self over the next few weeks.

## Time for Practice

### Soothing Rhythm Breathing (Audio Track 3)

When our nervous system is over aroused, breathing becomes shallower and quicker, and that increases the tendency towards anxiety or irritation. In contrast, when we slow and deepen our breathing, we engage a different system (our soothing or 'rest and digest' system). This helps us to feel calmer and more at ease with ourselves. Learning to train our minds and bodies to become more in-tune with our soothing system can be very helpful for well-being and for cultivating the compassionate self. So together by focusing on slowing and deepening our breathing, we are now going to try to create a sense of stillness within. The following exercise will guide you through a short training exercise in soothing rhythm breathing. This is a helpful breathing rhythm for beginning working on compassion.

The way we breathe can have a great impact on our body. When we are anxious and stressed breathing becomes shallower and quicker and this keep our anxiety and stress levels high. Learning how to breathe in a way that stimulates our soothing system can be useful because it provides a basis for the development of our compassionate self. Let's practice a way to breathe that involves deliberately slowing down our breathing and grounding our body.



*First, sit comfortably with your feet flat on the floor, about a shoulder's width apart, and your back straight and head in line as we learn just now. Your posture is comfortable but up right because the idea is to become relaxed but also to stay alert rather than to become floppy or sleepy. Gently close your eyes, or look down at the floor or allow your gaze to be unfocused if you prefer.*

*Now focus on your breathing, on the air coming in through your nose, down into your stomach, staying a short while and then moving back out through your nose. Notice how your stomach moves gently in and out as you breathe.*

*For the development of soothing rhythm breathing, we will be breathing slightly slower and slightly deeper than you would normally. The in-breath is often about 4-5 seconds ... hold ... and then take 4-5 seconds for the out-breath.*

*You might try to breathe a little faster and then a little slower until you find a breathing pattern that is comfortable for you and has a gentle rhythm to it – giving you the feeling of 'slowing down'. Ideally you want to get to about 5-6 breaths per minute.*

*Let's practice this for one minute.*

*When you breathe out, let it be a gentle collapse rather than anything forced – like a paper bag just gently letting air out.*

*Focus particularly on the out breath and the air leaving your nose with a steady rhythm. Try to ensure that the in breath and the out breath are even and don't rush them. **(Continued overleaf)***

*Continue to practice this for another minute.*

*As you develop your rhythm, notice and focus on the feeling of inner slowing with each out breath. Notice how your body responds to your breathing, as if you are linking up with a rhythm within your body that is soothing and calming to you. Notice how this links to your friendly facial expression.*

*Let's practice that for half a minute.*

*Now we can just 'ground ourselves for a moment'. Sensing the weight of your body resting on the chair and the floor underneath you. Maybe notice how your body feels slightly heavier in the chair now that you have slowed your breath.*

*So, in this moment then, allow yourself to feel held and supported...coming to rest in the present moment...staying alert with good body posture.*

*Feel the stabieness in your body that has come from the slowing and feeling slightly heavier. Also try to sense the capacity for inner stillness or stilling – like the calmness of a lake or a tree – still, without wind.*

*Remember that it is perfectly ok for your mind to wander. Simply notice it happening and then gently guide your attention back to an awareness of your body and breathing steadily in and out just sensing the flow of air coming in and out of your nostrils...just gently observing...just allowing things to be as they are. Feeling your body slowing down.*

*When you are ready, you are welcome to open your eyes and gently stretch your body.*

**Suggestion:**

As suggested above, soothing rhythm breathing can be practiced at any moment, on the bus, train, or even when taking a shower.

The more you practice noticing how your breathing affects your body, the more you will get used to slowing down. Sometimes it's important to remember to slow down using our breath even for only 30 seconds or one minute. The more we practice, the more we get used to slowing our body but also keeping our mind alert.

Keep in mind that slowing down doesn't mean that you will mentally slowdown, in fact this breathing can help you be more alert and concentrate, because when calm, you engage the thinking part of your brain (e.g., the frontal cortex) more easily.

**You can make notes here immediately after your practice, to remember anything that you noticed as you were trying exercise three.**

**Write any thoughts here:**

#### Mindfulness (Audio Track 4)

Before we begin cultivating our compassionate self, we first begin by training in mindfulness. Mindfulness is paying attention, with purpose and intention, to the activity of our mind a non-judgmental way – we take a step back and notice whatever comes to mind without being carried away by our automatic and usual reactions and comments. Mindfulness practice promotes the development of internal stability, which is an important foundation for compassion training. The starting point for mindfulness training is to simply notice what is happening in our minds in this moment. So, let's see if we can develop our observing mind, through the following practice:



*Sit comfortably in your chair with a stability and alertness posture, as practiced before. Adopt a friendly facial expression, and a slight smile. Try to focus on the sensations of your body slowing down, becoming heavier and stable.*

*Now try to find a breathing rhythm that is comfortable and natural to you and bring your attention to your body.*

*Note the sensations that are present in the body at this moment. You may notice sensations of pressure for example, the weight of your body against the chair, tension (for example, in your shoulders and neck), or more vague sensations of tingling or palpitations in some areas of your body.*

*Try to be aware of these sensations as if you were feeling them from within (from your mind's eye) and not by thinking about them.*

*Rest in this awareness of the body for one minute or so, noticing only these different sensations.*

*Now that you are completely immersed/rooted in your body, let go of any goal or intention and only observe what emerges in your awareness.*

*Notice what happens to your mind. When you do this, you may notice how it so easily wanders away to all kinds of thoughts and feelings arising or to sounds and smells from the outside world.*

*It is likely that sooner or later your attention will wander to any thoughts or feelings that appear in your mind.*

*For the next minute, simply try to notice when your mind wanders to thoughts or feelings, and gently bring it back to your body.*

*The sensations in your body are like an anchor for when your mind wanders and gets lost in your thoughts. Keep the intention of not having any goal or purpose and just be present in your experience of this moment with your thoughts and sensations, without judging them. Just being.*

**(Continued overleaf)**

*Let's practice this for one minute.*

*So, the key thing really is notice how you can wake up to observe your mind has wandered. This observation is the important thing, not the fact that your mind wandered or not.*

*These practices help us to become more observing and more fully present with our experiences of the outside (which come to us in our senses) and the inside worlds.*

*Reflect for a moment on how this practice was for you.*

*You may have noticed that the mind is always moving and has difficulty staying in the present moment. And this is not our fault.*

*However, although we cannot control what emerges in our mind, we can choose where to focus our attention, and this will change our whole experience.*

#### **Mindfulness and the senses:**

We can also use any of the senses to help us ground us in the present moment. So, for example lay, sit or stand for one minute and just listen – to any sounds that come to you - just listen to whatever sounds are in this moment for you. Try to be non-judgemental, just experience whatever there is to experience.

You can then do the same with your vision. Just notice the lights and the colours around you without judgement.

You can also practice this while you're walking. When you go walking notice the sounds and the colours around you without judgement – just being fully aware of the senses of the present moment.

Sometimes when our thoughts become troubling, it helps just to bring attention to the stillness of the present moment – to just let our thoughts go and leave them alone.

You can make notes here immediately after your practice, to remember anything that you noticed as you were trying exercise four.

Write any thoughts here:



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### **WEEK 3**

#### **Developing your Compassion Self (with preparation guide)**

##### **Chapter Aims:**

- To have a go at building your compassionate self.
- To talk through some things to keep in mind before you start.
- To introduce a daily exercise to develop your compassionate self.

##### **What's the reason for this chapter?**

This chapter is an important one – it's time to start to build your compassionate self. By engaging in this practice daily, I wonder what benefits you might notice?

I advise that you read the 'preparation for practice' in advance of trying the exercise this week, to think through some important bits to keep in mind before you start. Don't forget that the more you practice your compassionate self, the easier it will become.

### **Building your Compassionate Self**

It's great that you're reading this because this means you've picked up the book again! Now, the exercises over the coming weeks are designed to help you tap into your inner compassionate abilities and build inner compassionate qualities – to foster your compassionate self. To do that we are going to focus on our use of **imagery**.

We use imagery because we know that what we imagine can have powerful effects on our bodies and our minds. For example, if we are hungry and see a meal, this can make our stomach rumble and our mouths might salivate. But equally, if we just fantasise about a meal in our minds, then just imagining the food can also cause the same body response.

So how and what we imagine then is going to have a considerable impact on our bodies and brains. When we criticise ourselves, we release stress hormones in much the same way as if others were criticising or bullying us.

Compassionate imagery can work in the same way – if we focus our minds on compassionate themes and ideas, this will affect our feelings and body sensations. Research shows that if we focus on feelings of caring and being cared for, this can have a range of beneficial effects on our minds, feelings and bodies. For example, the more we focus on compassion and support for each other and ourselves, the happier and healthier we tend to be. We also know that regular practice can change how our brains function. In the same way as practicing an activity like playing an instrument or strategy game changes the way our brain is wired, so too does practicing compassion.

#### **Quick note:**

When we use the word “imagery”, we don't necessarily mean vivid pictures in the mind (some people may struggle to do this). Instead, this is more about creating a “mental experience”, whether that is through pictures, feelings, hearing words or phrases... the list goes on!

**Exercise:** Before we go any further, let's check in! Write down any thoughts (including worries) you have about building your compassionate self here:

### Preparing for Practice: Things to think about

I wonder what thoughts you are having about starting. There are lots of different 'mini selves' that may take charge when we prepare to do something new. Our competitive self might be thinking "bring it on!". Our anxious selves might wonder "what if this doesn't work?" and our critical selves might wonder "what if I do it wrong?".

**Let's go over some common worries and do some problem solving before you get started:**

- It is very normal for our mind to wander all over the place, especially when using your imagination or trying to focus. This can be a good thing sometimes: it can be linked to creativity, and it can help us to think about a range of things at the same time.
- You aren't doing it 'wrong' if your mind wanders. In fact, noticing it wandering is part of the training!
- When we are doing any of the exercises, the most helpful thing is to simply notice if your mind has wandered and return your attention to what you were focusing on.
- **You're not trying to empty your mind of thoughts. You're just noticing where your mind is, and then directing it gently to the exercise.**
- Keep in mind that the kinder, gentler, and more accepting you are of your wandering mind, and the less you try to force it to pay attention, the easier you may find these exercises over time.
- When you notice your mind has wandered, there's a moment where your mind feels like it's 'waking up'. This is the time to remind ourselves what we want to focus on.
- The most important thing is to try. Focusing your attention will be easier on some days, and harder on others. But keeping up with practice is key.

**What if my mind keeps wandering and I lose attention?**



**Being a parent is super busy! I'm never going to find the time...**

- Life can get busy! Sometimes so busy that we stop putting time aside to be kind to ourselves or try these practices. This is common and we're all like this.
- But there is most often a way of finding a moment to practice throughout the day. Times where we get two minutes of peace, whether that is whilst waiting for the bus, taking a shower, having a coffee break or even first thing in the morning or last thing at night whilst in bed.
- Ways of prompting yourself to try these exercises can help too. Things like a post-it note in a place you'll see, or an alarm reminder on your phone, or carrying a small object in your pocket, which every time you feel it, this may remind you of your compassionate self.
- **Small steps and regular practice are the key to success. The more we practice, the easier it may become (and the more committed to the ideals of compassion we become, which brings us greater fulfilment).**



**What if I get distracted by an interruption partway through?**

- Firstly, it can help to plan ahead and work out the best time to practice the exercises with minimal distractions. Where will you be? What time of day? What else might happen at this time? How can you limit distractions? Can you put your phone on silent? Are any family members around?
- However, despite the best planning, sometimes distractions are unavoidable. In this case, I'd say that what you do next will depend on the kind of distraction you experience.
- **In all instances, the important thing is to briefly pause and think "Is this interruption more important than what I'm currently doing?"**



- If the answer is yes (e.g., your child needs immediate assistance), you are welcome to stop the practice and manage the interruption. You can always come back and restart the exercise later.
- If the answer is no, take a deep breath and try to gently bring your attention back to the exercise and carry on.
- The most important thing is to try. Sometimes this can be easier or harder on different days. You can always have a break and try the exercise again.

**What if I struggle to make a clear picture in my mind?**

- A common worry people have is about not making clear pictures in the mind. Then they might start thinking they aren't doing it right. This is because we often misunderstand what imagery is.
- Supposing I ask you 'what's a car?' How would you answer that? What popped into your mind? It could be a fragmented picture of different cars, or car parts (wheels, doors, mirrors), or words and phrases about cars.
- **Imagery is like fleeting, fragmented impressions of pictures, words, phrases, parts. Imagery isn't in high definition.**
- Don't try to create fully formed pictures in your mind when you practice compassionate imagery.



Fleeting impressions and fragments are what come to us, these impressions are fine and it's more important that we focus on the feelings we are trying to generate with our images.

**What if I feel like I don't have the qualities needed to make a compassionate self right now?**

- This is a common worry. My advice is to start by getting into the mindset of being a method actor. To get into a character role, they would think about the character's typical voice tone and facial expressions, how they think and interact with the world.
- Try doing the same with the 'compassionate self'. Think about how this character might think, how it sees the world, what it says, its posture and its voice tone.
- Sometimes there are challenges along the way. We might start the day with good intentions, but later must manage a challenge that causes us stress, or anger, or sadness. Challenges are a normal part of life but try not to worry too much if other mini-selves take over – all you need to do is notice it happening and bring your attention back to your compassionate intentions.
- Did you know that actors use their own memories to try to recreate powerful emotions, and then bring their attention back to carry on the show. This is a great example of deliberate practice, the actor noticing it and bringing their attention back to focus on what they've got to do. You are in control of how much compassion you wish to bring to your life.
- **It doesn't matter if you feel you don't have the qualities. Instead, just imagine how you would be if you did have them. Imagining and thinking about how it would be to have the qualities of compassion might help you to create and experience your compassionate self.**



**Key points from this chapter:**

- Building your compassionate self takes lots of practice! Try the audio exercise at least once a day if possible.
- It's okay if your mind wanders – just notice it and bring it back.
- You aren't working towards a fully formed 'image' here – just whatever your brain comes up with!
- Have a think in advance about possible times of day where you could put this into practice – and how might you remind yourself to do it?

### Time for Practice

In the following practices, we will begin the compassion training. In these exercises we will learn to build and cultivate our compassionate self. Some people might find this exercise tricky. That's okay! Remember the tips throughout the book – the more you practice, the easier this should become.

We have split this exercise into a short version and an extended version. If you're finding it tricky, you might want to start with the short version first. The short version will help you to practice cultivating your compassionate self. The extended version starts the same too, but then you will move onto stating to practice channelling your compassionate self too. Try to do one of these exercises daily, and if possible, make sure you try out the long version too.

### Building and Cultivating the Compassionate Self

(Audio Track 5)



*In this practice, you will learn how to cultivate your compassionate self. To begin, choose a moment when you are unlikely to be disturbed for a while and sit comfortably. And you may like to close your eyes if you feel comfortable doing this.*

*So let us begin by remembering our body posture and breathing. So, get comfortable in your chair, feet flat on the ground, shoulders back, and chest open.. And focus on your soothing rhythm breathing, with the air coming in through your nose down gently into your stomach area and out through your nose again. Remember that this is breathing slightly deeper and slower than you would normally, about 4-5 seconds for the in-breath, and 4-5 seconds on the outbreath, and notice the feeling of your body slowing down.*

*Try to relax your facial muscles starting with your forehead, your cheeks and letting your jaw drop slightly. Then allow your mouth to turn upwards into a slight smile until you feel it is comfortable, a warm and friendly smile. Remember as we go through the exercise you may find your mind wandering. Do not worry about that, just gently and kindly bring it back onto the task we are doing.*

*And now imagine, as best you can, that you are a wise and compassionate person. It may be useful to bring to mind a situation when you felt compassion for another person. Try to remember what you thought, your feelings of kindness and care and your genuine wish for that person to be well.*

*Now, for a moment think about the qualities you would like to have if you were a deeply compassionate person. Remember it doesn't matter if you don't feel that you actually are a deeply compassionate person.*

**(Continued)**



*The most important thing is to simply imagine the qualities of a deeply compassionate person, and that you have them – you are stepping into this potential version of you, almost like an actor if you will stepping into this role of a compassionate character.*

*Let's practice this for about 10 seconds.*

*Now we're going to focus on some very specific qualities of compassion that you can add to your own personal and unique qualities you want to create in your compassionate self. These are the qualities of your compassionate wisdom, strength and commitment.*

*So the compassionate self has a deep wisdom that we all just find ourselves here part of the flow of life, with a tricky brain that can get is caught up in worry loops, anger and depression – and this is not your fault -- you have this wisdom right now and you understand other people could be like that too. So you have a wisdom of no-blame and judgment, but of openness and understanding that life is difficult and tricky at times.*

*Practice this for about half a minute.*

*Now try to imagine that your wisdom comes from a sense of strength and authority. Try to connect with an internal sense of strength, by focusing on your body posture and your soothing rhythm breathing. A solid posture, as if your body was a mountain, your breath a soft breeze, and your mind a clear and open sky. Feel the strength that comes from being supported by the earth beneath you. Notice how you feel when you imagine this sense of authority and trust in your body. Imagine how you would talk if you had this authority, how you would move in the world, how you would express this strength, this maturity, this confidence.*

*Practice this for about half a minute*

*Now based on this strength, authority, and wisdom, try to focus on your commitment to be compassionate, and your desire to be helpful to people, to use wisdom and strength where you can and help others, as well as yourself.*

*Practice this for about half a minute*

*Based on your wisdom, strength, and commitment, try to imagine that you have the courage to face difficult experiences. Imagine that you are willing to deal with difficulty, with no blame or criticism, and that you are willing to take responsibility for your life. For a few moments, keeping your friendly facial expression and voice tone, gently imagine that you are this person with a deep commitment and responsibility to deal with your mind and your life.*

**(Continued)**

*Practice this for about half a minute*

*Notice how you feel when you imagine yourself like this, with these compassionate qualities. Remember it doesn't mean that you actually feel like this now; we are simply imagining what it would be like to be this way, a compassionate person.*

*And now, as way to finish this exercise, let go of any attempt to visualize and for a few moments just return your focus to your breathing, and when you feel ready, you can open your eyes and gently stretch your body.*

*(and finish the practice).*

**You can make notes here immediately after your practice, to remember anything that you noticed as you were trying this week's exercise.**

**Write any thoughts here:**

**Building and Cultivating the Compassionate Self – extended version**  
**(Audio Track 6)**



*In this practice, you will learn how to cultivate your compassionate self. To begin, choose a moment when you are unlikely to be disturbed for a while and sit comfortably. And you may like to close your eyes if you feel comfortable doing this.*

*So let us begin by remembering our body posture and breathing. So, get comfortable in your chair, feet flat on the ground, shoulders back, and chest open.. And focus on your soothing rhythm breathing, with the air coming in through your nose down gently into your stomach area and out through your nose again. Remember that this is breathing slightly deeper and slower than you would normally, about 4-5 seconds for the in-breath, and 4-5 seconds on the outbreath, and notice the feeling of your body slowing down.*

*Try to relax your facial muscles starting with your forehead, your cheeks and letting your jaw drop slightly. Then allow your mouth to turn upwards into a slight smile until you feel it is comfortable, a warm and friendly smile. Remember as we go through the exercise you may find your mind wandering. Do not worry about that, just gently and kindly bring it back onto the task we are doing.*

*And now imagine, as best you can, that you are a wise and compassionate person. It may be useful to bring to mind a situation when you felt compassion for another person. Try to remember what you thought, your feelings of kindness and care and your genuine wish for that person to be well.*

*Now, for a moment think about the qualities you would like to have if you were a deeply compassionate person. Remember it doesn't matter if you don't feel that you actually are a deeply compassionate person. The most important thing is to simply imagine the qualities of a deeply compassionate person, and that you have them – you are stepping into this potential version of you, almost like an actor if you will stepping into this role of a compassionate character.*

*Let's practice this for about 10 seconds.*

*Now we're going to focus on some very specific qualities of compassion that you can add to your own personal and unique qualities you want to create in your compassionate self. These are the qualities of your compassionate wisdom, strength and commitment.*

**(Continued)**

*So the compassionate self has a deep wisdom that we all just find ourselves here part of the flow of life, with a tricky brain that can get is caught up in worry loops, anger and depression – and this is not your fault – you have this wisdom right now and you understand other people could be like that too. So you have a wisdom of no-blame and judgment, but of openness and understanding that life is difficult and tricky at times.*

*Practice this for about half a minute.*

*Now try to imagine that your wisdom comes from a sense of strength and authority. Try to connect with an internal sense of strength, by focusing on your body posture and your soothing rhythm breathing. A solid posture, as if your body was a mountain, your breath a soft breeze, and your mind a clear and open sky. Feel the strength that comes from being supported by the earth beneath you. Notice how you feel when you imagine this sense of authority and trust in your body. Imagine how you would talk if you had this authority, how you would move in the world, how you would express this strength, this maturity, this confidence.*

*Practice this for about half a minute*

*Now based on this strength, authority, and wisdom, try to focus on your commitment to be compassionate, and your desire to be helpful to people, to use wisdom and strength where you can and help others, as well as yourself.*

*Practice this for about half a minute*

*Based on your wisdom, strength, and commitment, try to imagine that you have the courage to face difficult experiences. Imagine that you are willing to deal with difficulty, with no blame or criticism, and that you are willing to take responsibility for your life. For a few moments, keeping your friendly facial expression and voice tone, gently imagine that you are this person with a deep commitment and responsibility to deal with your mind and your life.*

*Practice this for about half a minute*

*Notice how you feel when you imagine yourself like this, with these compassionate qualities. Remember it doesn't mean that you actually feel like this now; we are simply imagining what it would be like to be this way, a compassionate person.*

*Now to develop this practice a step further I'd like you to imagine you're watching a video of yourself. You see yourself getting up in the morning. Now holding your position of kindness and compassion, watch yourself moving around your room and slowly getting on with your day. Try to notice how the person that you're watching (yourself) is troubled by self-critical feelings or thoughts, maybe shame or fear, troubles about relationships past or present. Try to just be in touch with the person you are watching – try to notice the struggle and the suffering, but maintain your position of inner calmness and wisdom.*

**(Continued)**

*In other words, looking out through the eyes of your compassionate self with the intention of being kind and helpful. Really get a sense of what this feels like, looking through the eyes of the compassionate self.*

*How would you respond to yourself when in pain or struggling? How would you respond to others? What would you say, how would you say it? Try to get a feel for what it would be like, to respond as your compassionate-self. It might be tricky, but just try to imagine, as best you can.*

*All we are doing is trying to get a feel for what it would be like, to be this compassionate person.*

*Now just letting that imagery go and return slowly back to our breath, noticing the rise and fall of our belly, and noticing the contact our body makes with the chair. Getting a greater sense of the room and space around us.*

*It is important to recognise that this compassionate self is one aspect or one pattern within us. And sometimes this pattern gets washed out by all these other parts of us that want to run the show, things like anger, anxiety, or depression. These are patterns that are created within us, in our bodies and brains.*

*So sometimes it is really helpful, to deliberately, try to create the compassionate pattern, as the way to help with the difficult struggles we experience.*

*You don't need to spend very long to cultivate your compassionate self either, you can do it anywhere. It is about trying to remember to build it into your daily life, almost like building a compassionate habit. So just pausing at different times, at times of struggle, and connecting with our posture, our soothing rhythm breathing, and the intention of our compassionate-self. And bringing it to those moments of disappointment and struggle so we can be helpful and compassionate to ourselves and others.*

*And now, as way to finish this exercise, let go of any attempt to visualize and for a few moments just return your focus to your breathing, and when you feel ready, you can open your eyes and gently stretch your body.*

*(and finish the practice).*

**You can make notes here immediately after your practice, to remember anything that you noticed as you were trying this week's exercise.**

**Write any thoughts here:**

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## **WEEK 4**

### **Directing your Compassionate Self to Others**

#### **Chapter Aims:**

- To have a think about how you found the exercise last week.
- To introduce the idea that we can direct our compassionate self towards different people.
- To show you the next exercise to try daily over the next week.

#### **What's the reason for this chapter?**

Research is showing us that practicing our ability to direct compassion towards others can have lots of benefits for ourselves, as well as the benefits to whoever is receiving compassion from us. We're going to link this to the experience of parenting. Therefore, this chapter aims to support you to continue to practice creating experiences of receiving or giving compassion.



**But first, let's check in:**

Welcome back. Before we get started, I wonder how your first week of cultivating your 'compassionate self' went. How might your 'compassionate self' describe your experience of last week's exercises?

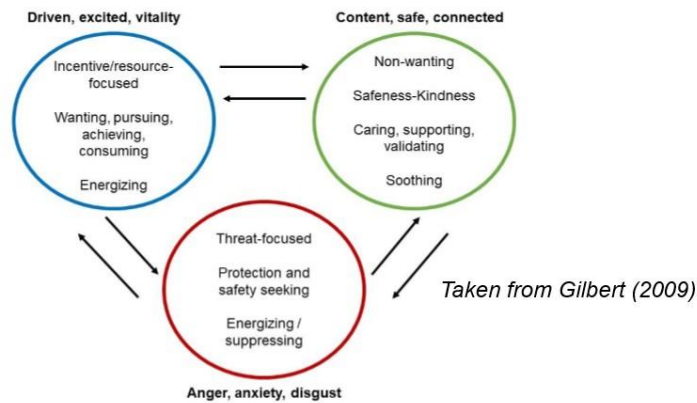
**Write any thoughts here:**

How do these thoughts compare to the ones you wrote down in last week's chapter? Have you noticed any change in how you understand or experience compassion? Now, we're still in the early days of developing your compassionate mind, and as discussed in chapter 3, this can take a lot of practice.

An important thing to recognise here is that however your compassionate mind practices went last week, you have nevertheless returned to this booklet. You've made it to chapter 4 and have probably tried some of the practices and opened your life to the possibility of training your compassionate mind, which are all big steps!

### Directing compassion to others

An interesting part of compassionate mind training is learning how we can direct compassion towards ourselves, but we can also direct it more widely to anybody and everybody. If we look back to the three emotion system circles in Chapter 1, you may notice that the soothing system is linked to feelings of safeness and connection with others.



Research shows us that by focusing on the wellbeing of other people, this can produce different benefits for ourselves, including:

- Increasing our social connection and support from others<sup>1</sup>.
- Even reducing some mental health difficulties, such as stress and anxiety<sup>2</sup>.
- It can feel good to share kindness with other people, as we know that we are helping them to feel better too<sup>3</sup>.

Many people find it easier to show compassion to other people rather than themselves – especially if we have a stubborn critical self! Thinking about parenting, many of us might naturally associate providing compassion, kindness and nurture to our own children and have seen the benefits of this too.

Now, there is less reading to do this week, but you'll need about 10 minutes daily to practice the exercise. However, you are welcome to look back over the previous chapters of the book. The following exercise involves thinking about a loved one and imagining directing compassion towards them. You could think of anybody: your child, a family member, a friend, a colleague, a famous person, a fictional character... the list goes on.

<sup>1</sup> Paul Gilbert. (2020). Compassion: From its evolution to a psychotherapy.

<https://doi.org/10.3389/fpsyg.2020.586161>

<sup>2</sup> Susanna Torbet, &... (2019). Self-compassion: a protective factor for parents of children with autism spectrum disorder. <https://doi.org/10.1007/s12671-019-01224-5>

<sup>3</sup> Gal Bohadana &... (2021). Self-compassion in mothers of children with autism spectrum disorder: A qualitative analysis. <https://doi.org/10.1007/s10803-020-04612-2>

### Time for Practice

#### Compassion for Others (Audio Track 7)

In the following exercises we will continue to cultivate the compassionate self. This time we will recall the compassionate qualities that we developed last week and activate them by imagining being this compassionate being in relation to others. Now let's practice focusing on our compassionate self.



*This is the practice of compassion for a close person.*

*To begin this practice, choose a moment when you are unlikely to be disturbed for a while and sit comfortably. Always remembering to respect the process and prepare the body.*

*So get comfortable in your chair, feet flat on the ground, shoulders back, and chest open. And focus on your soothing rhythm breathing, with the air coming in through your nose down gently moving your stomach out, and out through your nose again.*

*Remember that this is breathing slightly deeper and slower than you would normally, notice the feeling of your body slowing down. Spend about 4-5 seconds on the in-breath, and then about 4-5 seconds on the outbreath, or at a pace that feels comfortable for you.*

*Remember as we go through the exercise you may find your mind wandering. Do not worry about that just gently and kindly bring it back onto the task we are doing.*

*Spend a few moments using your soothing rhythm breathing.*

*Now bring to mind your compassionate self, with its qualities of wisdom, strength, and commitment.*

*Bring to mind someone you care about, to whom if feel genuine affection. It could be a child, friend, partner, another parent, perhaps of an autistic child, or even an animal. Hold them in your mind's eye.*

*Now as you're sitting in the chair with your compassionate self, focus your compassionate feelings on them. You wish for them to be happy and free from suffering, to feel fulfilled and peaceful.*

*With a compassionate facial expression and voice tone, name them in your mind as you breathe in and out.*

*When you're ready, say the following on the out breath:*

**(Continued overleaf)**

**May you be free from suffering (again say their name)**

*(and breathe in)*

**May you be happy (again say their name)**

*(and breathe in)*

**May you flourish (and say their name)**

*(and breathe in)*

**May you live with ease (and say their name)**

*Don't worry if you can't remember all the sentences. Just focus on the ones you can. The sentences are not the most important thing – what matters is your genuine wish and your compassionate feelings. Let's do it again:*

**May you be free from suffering (again say their name)**

*(and breathe in)*

**May you be happy (again say their name)**

*(and breathe in)*

**May you flourish (and say their name)**

*(and breathe in)*

**May you live with ease (and say their name)**

*Maybe you notice feelings of satisfaction and joy when you imagine that the other person is happy, free from suffering, and living with ease. But if not, don't worry about it; what matters is to cultivate this intention that the other person is well.*

*Now, when you feel ready, let the image of the other person fade. Spend a moment or two reflecting on the feelings that have arisen in you from focusing your compassionate feelings on someone you care about. Notice how that feels in your body.*

*For a few moments just return your focus to your breathing, and when you feel ready, you can open your eyes and gently stretch your body.*

**You can make notes here immediately after your practice, to remember anything that you noticed as you were trying exercise six.**

**Write any thoughts here:**

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## **WEEK 5**

### **Directing Compassion to Yourself**

#### **Chapter Aims:**

- To have a think about how you found the exercise last week.
- To practice directing the flow of compassion towards us.
- To show you the next exercise to try daily over the next week.

#### **What's the reason for this chapter?**

This chapter aims to support you to start thinking about how you can direct the flow of compassion to yourself. It builds on the exercises you have tried over the last two weeks.

**But first, let's check in:**

Welcome back – it is so exciting that you're here and reading chapter five. Just like last week, let's start by reflecting on how you found the last week. I wonder how directing the flow of compassion towards other people went. How might your 'compassionate self' describe your experience of last week's exercises?

There are no right or wrong answers here. The main thing is to just notice how you've found it.

**How did it go? What was it like to practice the compassion to others exercise? Write down any thoughts here:**

After you have written something above, now might be a good time to look back over your reflections from the last two weeks. I wonder what you might notice as you compare your thoughts about the exercises after spending more time practicing them.

As you read these back, you could wonder which mini-self had taken the stage as you'd written each reflection? Many of us might notice that our critical-self can take over when we reflect about our practice. This is a really common experience when we are starting something new. The important thing here is to notice this and think "*what might our compassionate self say here instead?*".



### Self-Compassion

The last few weeks have gradually helped you to think about the qualities of compassion, the theory of how it can help to support your wellbeing, how it relates to being a parent and how we can direct the flow of compassion to other people. We have thought about the role of the inner critic and how this can change how your feeling, how your body feels, and even how you might act.

This week's focus is to start to turn compassion inward towards yourself as a parent. Research is showing us that self-compassion is a powerful source of coping and increasing resilience when challenges (parenting and otherwise) appear in our lives.

For those people who might have a more persuasive self-critic, the idea of deliberately directing compassion towards ourselves might initially feel challenging or uncomfortable. However, the important thing to remember is that everybody has the ability to learn to be self-compassionate. Again, if we think back to what we know about the three emotion systems, we know that the more we practice getting our brain into a certain system, the more developed that system becomes (and the easier it is to move back into that system in the future).

Don't forget that you can check back through some of the top tips as you prepare for practice and keep these in mind.

#### Here are some reminders about the benefits of self-compassion:



### Time for Practice

#### Compassion for the Self (Audio Track 8)

In the following exercise, we will continue to cultivate the compassionate self and this time we will bring to mind the compassionate qualities that we developed last week, and activate them by imagining being this compassionate person in relation to yourself. Now let's practice focusing on our compassionate self.



*In this practice, you will learn to cultivate compassion for yourself.*

*To begin this practice, choose a moment when you are unlikely to be disturbed for a while and sit comfortably. Always remembering to respect the process and prepare the body.*

*So, get comfortable in your chair, feet flat on the ground, shoulders back, and chest open. Focus on your soothing rhythm breathing, with the air coming in through your nose down gently moving your stomach out, and out through your nose again. Remember that this is breathing slightly deeper and slower than you would normally, notice the feeling of your body slowing down.*

*Remember as we go through the exercise you may find your mind wandering. Do not worry about that. Just gently and kindly bring it back onto the task we are doing.*

*Practice your soothing rhythm breathing for about half a minute.*

*Now bringing to mind your compassionate self, with its qualities of wisdom, strength, commitment, try to picture a photograph of yourself. Focus a sense of compassion on you – you as a fellow human being that has arrived in this world doing the best you can. You're sometimes confronted with difficult feelings or life circumstances, and sometimes you can feel overwhelmed and stressed.*

*Now with a compassionate facial expression and voice tone, keep this image of yourself in your mind. As you breathe in and out, say the following on the out breath:*

**May I be free from suffering.**

*(then breathe in)*

**May I be happy.**

*(then breathe in)*

**May I flourish.**

*(then breathe in)*

**May I live with ease.**

**(Continued overleaf)**

*If at any point you feel yourself pulled into those difficult feelings or life circumstances, just come back to the compassionate self that stays with a sense of authority, calmness, maturity and wisdom. Let's say those again:*

**May I be free from suffering.**

*(then breathe in)*

**May I be happy.**

*(then breathe in)*

**May I flourish.**

*(then breathe in)*

**May I live with ease.**

*For a minute, just practicing saying those things, directing those feelings to yourself on the outbreath. To be free of suffering, to be happy, to flourish, to live with ease. Don't worry if you can't remember them all. Just focus on the one's that you can.*

*Now, when you feel ready, let the image of yourself fade. Spend a moment or two reflecting on the feelings that have arisen in you. Notice how that feels in your body.*

*For a few moments just return your focus to your breathing, and when you feel ready, you can open your eyes and gently stretch your body.*

**You can make notes here immediately after your practice, to remember anything that you noticed as you were trying exercise seven.**

**Write any thoughts here:**

*(page intentionally left blank)*

## **WEEK 6**

### **Taking your Compassionate Self along the journey of Parenthood**

#### **Chapter Aims:**

- To reflect on how the last five weeks of compassionate mind training has been.
- To begin to plan how you may wish to bring your compassionate self along your parenting journey as the workbook reaches its end.
- To have a go at a final exercise to try (this one involves writing)

#### **What's the reason for this chapter?**

Although this is the last week of the workbook, you are at the start of a much longer journey to cultivate your compassionate self. This final part of the workbook helps you to start to plan how you can take forward your learning from the last few weeks. The chapter ends with a compassionate letter writing exercise, which you might want to keep as a reminder of your journey.

**You are reaching the end of this workbook.**

It is great that you have reached this far through the workbook. If this has taken longer than planned, or you haven't quite reached this chapter yet, that is okay. We have recognised that part of parenting involves constantly prioritising and managing different responsibilities, and so in despite of this, by picking up this booklet you have been able to bring your attention back to compassion.

As you've learnt through reading each section of the workbook and trying out the practical exercises, small steps and regular practice are key to success. I hope that you have been able to experience some of the benefits of the compassionate self. Of course, just because you have finished reading this workbook, you are still able to look back over sections and practice whichever exercises you would like to, as this resource remains available to you. Your journey is ongoing, and you can make the choice to continue to set a few minutes of your day aside to be compassionate to yourself or others.

Let's use this week to reflect on what you have learned over the last few weeks. Then I have a final exercise for you to try out.

**Spend some time thinking about all you have learned about your compassionate mind over the last five weeks.**

**Then write down below at least three key things you have learned (about compassion, about parenting, or even about yourself!):**

**How has your 'compassionate self' developed over the last 5 weeks? What did you notice as you worked through the exercises? Did it get easier, or harder, or stay the same? What might have influenced this?**

*(You could write down some example situations where you've allowed the compassionate self to take the stage.)*



**Finally, how might you plan to take your compassionate self forward through life?**

*(You might need to think about how often and how long you want to practice. What time of day worked best for you? Did you set any reminders? Which practices did you prefer? How did you make them work for you?)*

## Time to Practice

### Compassionate Letter Writing

The point of compassionate letter writing is to help you to bring your compassionate self to your attention and have a go at being kind, helpful and supportive to yourself. By practicing this, we embody our compassionate self and feel the benefits of the soothing system coming online.

A great thing about expressive writing is that you can spend as much or as little time as you want doing it. It can be helpful to get thoughts down onto paper, and certainly many of us do that already by keeping diaries. Compassionate letter writing also creates a physical product that you can keep and re-read as many times as you want, especially during those moments where you might want some compassionate support in the future.

Now, some people might wonder about how we write a compassionate letter, or what ones might look like. The answer is that there are many ways that you can write the letter, but below are some top tips and an example to help you get started. Some people use a recent situation that has caused them distress, and then use the letter writing exercise to show understanding and acceptance towards themselves, and consider how to move forwards.

#### Tips for getting started:

1. Before you put pen to paper or fingers to keyboard, spend a few minutes thinking about your compassionate self and the qualities it has. Consider what you have learned about your compassionate self over the last few weeks: its posture, its facial expression, its voice tone. Maybe you could try one of the compassion exercises from the previous weeks to help you to move into this mindset. Just take as much time as you need.
2. Starting the letter is often the biggest hurdle. We might overthink about what to write, or tell ourselves we can't do it, or worry about spelling or how it looks on the page. There is no right or wrong method here, but a helpful way to start is to put "*Dear [your name], I know you have been feeling ...*" Then just let your hand write for itself and see what comes out (don't forget that whatever happens, you can always throw it away and start again!).
3. Throughout, you want to keep your mind compassionate self and all its qualities. The tone of your letter should be kind, warm, non-judgemental, wise, and understanding. If you notice your other mini-selves start to take over the exercise, recognise that this is normal and gently bring your attention back to your compassionate self.

4. As you write your letter, try to give yourself permission to accept and understand your distress. Let your compassionate self recognise the reasons why you experienced distress, to remind you that these feelings make sense. You might say something like *"I am sad that you feel (emotion) - it's understandable that you feel this way because...."*
5. As your letter continues, perhaps your compassionate self might write *"I would like you to know that..."* and provide some reflections from your compassionate self about your feelings and thoughts. Try to be open with them and develop a compassionate and balanced way of working with them.
6. Perhaps your compassionate self might reference some of your good qualities and strengths in your letter, whilst reflecting on your feelings and thoughts.
7. The letters shouldn't provide advice or tell you what you can and can't do. You don't need advice, as you likely know this already – but the letter is there to support you to act on it.
8. Basically, just write in a way that you would like somebody who is really understanding, calm, wise and kind to say to you.
9. Try not to get too caught up on whether you're doing the exercise correctly – there's no right or wrong approach, and there's no such thing as a 'perfect' letter. Also, these judgements might make it harder to do the exercise. If you're struggling with the flow set out in this chapter, you can always change it. Try just writing whatever comes to mind with little thought.
10. You can take your time to write the letter. You also don't have to write this letter all in one go; you are welcome to take breaks and come back.

#### **Checks for your compassionate letter writing**

- Expresses genuine concern and caring
- There is a genuine non-judgemental sense of warmth, kindness and care for yourself throughout
- Understanding and accepting of your distress and needs
- Responds to your distress using kindness and sympathy
- Helps you face how you're feeling and move towards tolerating this
- Supports you to be reflective of your difficulties, dilemmas and feelings

### Example Letter

Stacey suffered through a stressful situation where her child's teacher had requested a meeting and informed Stacey that the school continued to struggle to manage her child's behaviour. The school suggested that Stacey began to look for alternative school provision. Stacey felt devastated as her child had taken so long to finally settle into the school routine and this would be another big transition that he might not be able to cope with. She had also recently started a new job and became fearful that any potential time off from school would affect her work.

Stacey tried to avoid thinking about these stressful things for a week or so and tried to distract herself by keeping busy at home and work. However, one evening it all felt too much and she became tearful whilst at home, became self-critical and questioned herself, wondering if her child's behaviour was due to her parenting approach, or whether if she had noticed her child's difference earlier, perhaps he would have been seen earlier by services.

Stacey decided to write a letter from her compassionate self's point of view.

*Dear me,*

*I know I've been feeling so stressed lately and I think any parent would feel stressed too in this situation. It's understandable that I feel like this – I want my son to have a good childhood and a normal life, but I know he needs certainty, and suddenly everything feels all up in the air again, and he might have to move schools, which I think he won't cope with and that terrifies me. I guess in a way, I work best when I know what's happening too – I just want my child to be happy and okay, but also, I know that this might impact my routine at work, and I need the money to support the family. It feels like all my emotions are building up and spilling over and my thoughts just don't stop. This isn't because there is anything wrong with me, that's just a normal reaction to managing stressful situations – it is painful and very hard. It is compassionate for me to face these difficult feelings and learn to accept them for what they are, rather than try to fight against my feelings or question myself.*

*The more I think about it, the more I realise that my feelings are valid in this situation. My manager at work seems genuinely understanding and I wonder whether it wouldn't be that much of an inconvenience for me to talk about flexible hours if this is needed. I know if I was manager, I'd do the same for someone in my position. I have thought about how I can prepare my son for the possible change of schools, and I know that he manages better when given lots of time to process this and plan. As I think about it, I realise that I too need some time to work through things. So often I try to keep myself busy, but I recognise the importance of giving myself kindness and the time to process how I'm feeling. Right now, I can work through this and think about how I can look after myself, as well as my son over the next few months.*



### **Optional: Compassionate Object**

A compassionate object is something that can remind you of your compassionate self.

It's something that is meaningful to you. Something that you might find empowering, soothing, and calming. It is something that might bring on those qualities of your compassionate self, wisdom, strength, courage, and confidence.

It can be something personal to you, but here are some examples to get you thinking:

- A small stone or shell to carry in your pocket.
- A picture or drawing of your compassionate self.
- A compassionate quote or poem
- Something soothing – a nice smell or sound.
- It could even be your compassionate letter!

If it's small enough, you can keep your compassionate object with you. Some people might carry it in their pocket. This can be helpful, because any time that you need a reminder about your compassionate self, you can reach into your pocket and your object is right there.

Some people find more than one compassionate object. If you'd like, you could find several and make yourself a 'compassionate toolbox' using any box or bag filled with items that remind you of your compassionate self. You might want to start off with a few objects and build it up over time. The important thing is to keep it somewhere that you can see it, so you are often reminded of your compassionate self.

## Ending

As we come to the end of our journey together, I want to say well done for committing yourself to the process and getting to the end of this workbook, however long it has taken you. Although we are ending our work together now, I am excited to think about the next phase of your journey with your compassionate self through parenthood.

Please don't forget that we will all experience setbacks or frustrations from time to time. This is part of being human, and there is no right or wrong way to be. I hope that this workbook has helped you to recognise that your compassionate self can be there to help. I encourage you to keep returning to your compassionate self, as this can help it to grow. You can use it to notice and face difficulties to support yourself, your child, and others too. I sincerely hope that this can bring wellness and happiness to yourselves and others in times of difficulty.

Finally, you are always welcome to return to this workbook whenever you would like. You can continue to practice any of the exercises too. I would recommend that you keep your compassionate letter somewhere safe as well, to read again whenever you might need it. This workbook is always here for you. To quote the founder of compassion focused therapy: ***"may your compassionate mind serve you well"*** (Gilbert, 2009).

Many compassionate wishes,

Fran

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*The Compassionate Mind Workbook: A step-by-step guide to developing your compassionate self*. By Chris Irons and Elaine Beaumont (2017). Publisher: Robinson.

[www.compassionatemind.co.uk](http://www.compassionatemind.co.uk)

**Poster**





# Adapting Compassionate Mind Training into Guided Self-Help for Parents of Autistic Children

**Acknowledgements:** The research team would like to thank Dr James Kirby for providing permission to adapt an existing compassionate mind training resource for parents<sup>1</sup> during this study.

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## Background:

- Parents of autistic children (PAC) are at increased risk of psychological distress, including shame and self-criticism.<sup>2</sup>
- Poor parental mental health can adversely affect parent-child interactions, their attachment relationship, and child developmental outcomes.<sup>3</sup>
- PAC experience multiple barriers to accessing direct psychological interventions.<sup>4</sup>
- Compassion Focused Therapy (CFT) is a recommended transdiagnostic intervention for high shame and self-criticism.<sup>5</sup>
- There is limited quality research around the use of CFT with PAC and no systematically adapted PAC-specific CFT resources.

## Research Questions:

**How can an evidence-based CFT resource be adapted into a guided self-help intervention for PAC, whilst maintaining theoretical coherence, for further investigation during feasibility testing?**

**What are stakeholder views regarding the anticipated factors influencing successful implementation of the CFT resource during future feasibility testing?**

## Method:

**Participants:** 7 PAC and 4 Clinical Psychologists (CPs) working in children's autism services (UK-based) and 1 international CFT expert.

**Recruitment:** Social media, support groups and charity organisations, and professional networking.

**Procedure:** Five iterative phases of stakeholder feedback via written commentary and focus groups, and intervention refinement.

**Analyses:** Directed Content Analysis<sup>6</sup> was used to extract suggested adaptations from stakeholder feedback. Framework Analysis<sup>7</sup> was used to define anticipated factors influencing feasibility test implementation.

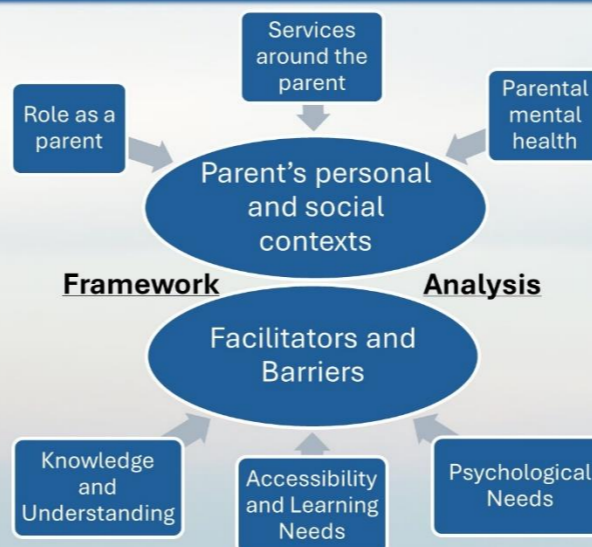
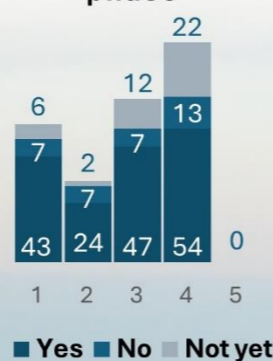
## Discussion:

- This study was the first to document the stakeholder-informed adaptation process for a theoretically coherent guided self-help CFT intervention for PAC: **Compassionate Mind Training for Parents of Autistic Children (CMT-PAC)**.
- The therapeutic relationship between PAC and the workbook was emphasised as a key facilitator for retention, cultivated through modelling a compassionate stance in the text.
- Fear of compassion may reduce engagement with self-directed practices, which will require further consideration during feasibility testing.
- PAC engagement may fluctuate due to contextual factors, so the promotion of flexibility is an anticipated facilitator. Adherence to protocol requires further thought.
- Increased prevalence of neurodivergent PAC was raised, involving queries about abilities to do imagery and body-based CMT practices.

## Results:

### Content Analysis

**Adaptations implemented per feedback phase**



## Future directions:

**How suitable, acceptable, and feasible is CMT-PAC in practice? What is the impact of CMT-PAC on parent's compassion to self and others, parental stress and their mental health?**

## References:

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