PROFESSIONAL DOCTORATES

Growing Kind Minds: Adapted group Compassion Focused Therapy for Adults with Intellectual Disabilities (CFT-ID)

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Growing Kind Minds:

Adapted group Compassion Focused Therapy for Adults with Intellectual Disabilities (CFT-ID)

Neil Clapton

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This thesis is submitted in partial fulfilment of the regulations for the

Doctorate in Clinical Psychology

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SECTION 1

Thesis Abstract

This thesis explores the development and adaptation of Compassion Focused Therapy (CFT) groups for adults with Intellectual Disabilities (ID).

A narrative systematic review of the literature focused on how shame and shame-based processes may play a significant role in the development and maintenance of psychological distress in adults with ID. The review identified 17 relevant studies that had investigated shame in some form. Findings indicated that adults with mild to moderate ID appear to experience both external and internal shame, and that this was associated with elevated levels of psychological distress. However, the scope of the review was limited by the fact that many studies were cross-sectional in nature, and that very little research involved clinical populations. The review concluded by attempting to synthesise the current available research into an explanatory biopsychosocial model of how shame develops in adults with ID, and recommending the development of compassion-focused interventions that might alleviate shame in this population.

The empirical study utilised a mixed methods design to investigate the feasibility and acceptability of adapting group CFT for adults with mild ID. Six participants completed session-by-session feasibility and acceptability measures, attended focus groups, and completed pre and post-intervention measures of self-compassion, psychological distress, and social comparison. Focus groups were analysed using thematic analysis, identifying four main themes: (1) motivations for attending; (2) direct group

experiences; (3) difficulties in being self-compassionate; and (4) positive emotional changes. Significant increases in overall self-compassion, and significant reductions in self-criticism and unfavourable social comparison, were found. Results indicate that CFT can be feasibly adapted for adults with ID, and is experienced as a helpful intervention. Some issues remain surrounding level of understanding of some conceptual aspects of CFT, and whether this is relevant to outcomes. Implications for future research and clinical practice are further explored.

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Acknowledgements

Firstly, I would like to offer special thanks to all of the participants who contributed to this project, without which it would not have been possible. Their courage to share their difficulties, innate wisdom, and open-hearted support for each other never ceased to amaze me, and has taught me a great deal more about the nature and importance of compassion. The insights they have generated will deepen our understanding, and will no doubt benefit many others.

I would especially like to thank Jonathan Williams for his enthusiasm and commitment to the project from the start, and his contribution, guidance, and support throughout. He really made this project happen, for which I am eternally grateful. Special mention and thanks must also go to Gemma Griffith, whose guidance around the qualitative analysis was priceless.

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SECTION 2: Literature review

The role of shame in the development and maintenance of psychological distress in adults with intellectual disabilities: a narrative review and synthesis

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The role of shame in the development and maintenance of psychological distress in adults with intellectual disabilities: a narrative review and synthesis

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Running Title: Shame in adults with Intellectual Disabilities

Abstract

Background: The role of shame in the development and maintenance of psychological distress in adults with mild to moderate Intellectual Disabilities (ID) has been relatively under-researched. This paper provides a review of diverse current research that has implicitly or explicitly investigated shame processes in this population in some form.

Methods: A narrative systematic review of the literature was undertaken. An electronic search of four databases identified 17 studies that met the eligibility criteria.

Results: Findings indicate that individuals with mild to moderate ID experience both *external* and *internal shame*, which appears to be related to increased psychological distress. Experiences of being shamed may significantly negatively impact on self-to-self relating, processes of social comparison, subsequent self-worth and emotional well-being.

Conclusion: Shame may well be a significant contributory factor in the development and maintenance of psychological

distress and subsequent mental health issues in some adults with mild to moderate ID.

Keywords: intellectual disability, self-criticism, shame, social comparison, stigma

Introduction

It is well-documented in the scientific literature that individuals with Intellectual Disabilities (ID) historically have and continue to be subjected to experiences of stigma/stigmatisation, which can significantly impact on their psychological and emotional well-being (Ali et al., 2012; Ditchman et al., 2013; Werner et al., 2015). Much of the stigma research has focused on attitudes and beliefs *towards* people with ID, and/or the experiences of significant others (e.g. family members) from being associated with someone with ID, otherwise known as courtesy stigma. However, somewhat surprisingly, there appears to be relatively little research examining the impact of such stigmatising experiences on individuals with ID from a first-person perspective (Beart et al., 2005), or explanatory models that provide a comprehensive understanding of stigma processes for this population (Ditchman et al., 2013). Accordingly, there

appears to be scant research that explicitly makes reference to or examines *shame* in people with ID.

Defining shame and shame-based processes

Shame is a powerful, painful self-conscious affect characterised by feeling inferior, undesirable, defective, worthless, powerless and exposed (Gilbert, 1998; Lewis, 1992; Tangney & Fischer, 1995). Some authors have tended to focus on shame as a self-focused, self-evaluative experience of the entire self as being defective or inadequate in some way (Tangney & Dearing, 2002). However, shame typically begins in the eyes of the other, or more specifically how we feel we exist in the minds of others (Gilbert, 1998, 2003). Shaming experiences are analogous to stigma, in that this involves the experience of being socially criticised, rejected, excluded, isolated, humiliated, denigrated, and subordinated by others.

Gilbert (2003) suggests that, from an evolutionary perspective, shame is related to the competitive dynamics of life and the need to prove oneself acceptable/desirable to others. Shame may be part of an evolved (social) threat detection system that alerts us to the possibility that we are existing negatively and/or not eliciting enough positive feelings in the minds of

others, feeling exposed, and vulnerable to attack, punishment, marginalisation, rejection, ostracism, and exclusion (Gilbert, 2014). Shame thus signals a threat to the social bond (Scheff, 2000), given that acceptance and belonging is crucial to the survival and well-being of all mammals (Baumeister & Leary, 1995). This typically results in the activation and development of defensive self-protective strategies/responses, such as social anxiety and depression (Gilbert, 2000), to protect oneself from further experiences of shame and/or complete social rejection. Other conceptualisations, whilst agreeing that shame reflects a concern with the threatened self, have attempted to link shame to more positively-oriented approach-related motivations and behaviours than defensive ones (De Hooge et al., 2009).

Shame typically involves two key components:

(1) *External shame*, which refers to how others see the self, or how we exist in the minds of others (Gilbert, 1997, 1998). External shame arises primarily out of the experiencing of shaming by others on the self (Gilbert, 1998, 2003). Attentional focus is on the (mind of) other, believing that others view the self negatively, leading to feelings of being rejected and/or feeling vulnerable to attacks from others. This

dimension of shame relates to stigma consciousness and awareness/perception (Pinel, 1999);

(2) *Internal shame*, which refers to how one exists in one's own mind and how one exists *for* others, where the attentional focus is on the self, and how the self judges and feels about the self (Gilbert, 1998, 2003). Internal shame is thus related to negative self-evaluative processes (such as self-criticism, self-devaluation, and negative social comparisons) and self-directed affects (e.g. self-directed anger and contempt, self-hate, self-disgust), and the self is experienced as unattractive, inadequate, bad, or flawed (Gilbert, 1998). This can also be conceptualised as the *internalisation* of shame (Gilbert, 2003), which is analogous to internalised stigma or self-stigma (Ali et al., 2012). Evolutionary-speaking, such self-evaluative processes are self-protective/defensive and submissive strategies to limit the social damage (e.g. further attacks and/or complete rejection) from social threats (Gilbert, 2000).

Thus, shame relates to existing negatively in the minds of others, but also existing negatively in our own minds. External and internal shame are highly correlated and are often fused together (Lewis, 2003). However, it is also possible to experience these two aspects completely separately. For

example, one can feel okay within oneself and not personally ashamed by one's own behaviour, whilst knowing that others find oneself or behaviours shameful. Therefore, internal and external shame are highly related, over-lapping but separate constructs.

When contrasting stigma and shame, stigma relates to the *social* dimension of shame. Specifically, the process of stigmatisation is where individuals are globally devalued and marginalised by others because they are deemed to hold attributes, characteristics or values that deviate from the dominant cultural/societal norms (Kurzban & Leary, 2001). This relates to Goffman's (1963) idea of stigma as a 'spoiled identity', where there is a global attribution about the whole self as being bad and defined by that stigma. Stigma is thus a *cause* of shame (Lewis, 1998).

Shame also differs from guilt, in that both involve different motivations, attentional focus, functions, and behaviours (Gilbert, 2003; Kim et al., 2011). Guilt typically involves a focus on the hurt caused to the other, one's behaviour (rather than the 'whole self'), feelings of sadness/sorrow/remorse, and a desire to repair or make amends.

The role of shame and shame-based processes (e.g. self-criticism) in the development and maintenance of

psychological distress and mental health issues in adults is now increasingly acknowledged (Kim et al., 2011; Scheel et al., 2014; Kannan & Levitt; 2013). However, shame has received little explicit attention in the psychological literature in regards to adults with ID, other than in relation to the concept of secondary handicap (Sinason, 1992). Secondary handicap has been conceptualised as how a primary handicap (i.e. having ID) is compounded by defensive exaggerations of one's initial disability (i.e. the secondary handicap), where awareness of difference arising from others reactions or one's own mind leads to defensive responses as a way of coping (Jones et al., 2008).

Purpose of review

This paper will attempt to review whether and how shame (and shame-based process) may significantly contribute to the development and maintenance of psychological distress and mental health problems in adults with mild to moderate Intellectual Disabilities (ID). This will encompass a narrative review of related research that includes the experience of stigma (and its internalisation), socio-cognitive shame processes such as social comparisons and self-evaluative

threat, and the impact of shame/stigma on the self (in terms of self-concept and self-esteem).

To our knowledge, there are no narrative or systematic reviews relating explicitly to the concept of shame and shame-based processes in individuals with mild to moderate ID. Only one systematic review has been conducted that reviewed studies examining self-stigma in people with ID (Ali et al., 2012), and one narrative review of the literature around stigma and social identity from the perspective of individuals with ID (Beart et al., 2005). This review will attempt to update, complement and expand on these reviews by locating and re-conceptualising stigma through the lens and concept of shame. Accordingly, this review will attempt to synthesise relevant research into an overarching theoretical framework of how and why shame may contribute to psychological distress and subsequent mental health issues in people with ID.

The specific aims of this review are to:

(1) Evaluate how effectively research has identified and investigated the impact of *external* shame experiences on levels of psychological distress in adults with ID;

(2) Evaluate how effectively research has identified and investigated whether adults with ID experience *internal* shame, and/or engage in shame-related processes such as self-criticism, negative self-evaluations and social comparisons, and the level of impact this has on psychological distress;

(3) Identify what further research may need to be done to more thoroughly investigate the role of shame (and its amelioration) in the development and maintenance of psychological distress in this population.

Method

Inclusion and Exclusion Criteria

Specific inclusion criteria for the review included the following:

- Primary research investigating shame and shame-based processes (e.g. stigma, social comparison, self-criticism, self-evaluation) from the perspective of adults with mild to moderate ID
- Clinical and non-clinical populations
- Quantitative and qualitative methodologies

- Had to include more than 10 participants (to ensure some degree of methodological quality and generalisability)

Specific exclusion criteria included the following:

- Studies examining the attitudes of other groups towards people with ID
- Studies that specifically examined courtesy and affiliate stigma (e.g. family/carers' experience of stigma by association)
- Studies not specifically referring to ID (i.e. general disability, physical disability)
- Studies with child populations (as focus is adults with ID)

Search Strategy

Studies were identified by searching four online databases: Web of Science, ScienceDirect, PsycInfo, and ERIC (Proquest). Searches were conducted between the time period of December 2015 to February 2016. The search terms "intellectual disability OR learning disability" (using OR as the Boolean operator) were combined with (using AND as the Boolean operator) "shame OR stigma", "self-criticism OR self-

blame", "social comparison OR self-evaluation". These searches were limited to titles, abstracts, and keywords only. This initially resulted in the identification of 1019 papers, leaving 736 after duplicates were removed. Subsequently, titles and abstracts of all identified articles were carefully screened and reviewed for their relevance/applicability, and those that were not deemed relevant were removed from the list.

Additionally, reference lists of all included studies were searched to identify further potentially relevant studies for inclusion. The process for study selection is illustrated in detail in Figure 1 (see Appendix 2), in accordance with PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-analyses; Moher et al., 2015).

Figure 1 [INSERT HERE]

Quality Assessment

Given that the identified studies tended to be of mixed/heterogeneous methodologies, the STROBE checklist(s) (Von Elm et al., 2014) were used as an assessment and checklist of study quality for cross-sectional and case-control

studies, whilst the CASP tool (Public Health Resource Unit, 2006) was utilised for the appraisal and assessment of any qualitative studies.

Results

Overview of Studies

Table 1 (see Appendix 1) provides an overview and summary of the studies included in the review. A total of eighteen papers were included in the review, with varying methodologies including cross-sectional studies (*n*=8), between-groups comparisons (*n*=5), and qualitative methods (*n*=5). One study (Ali et al., 2015[1&2]) was reported across two separate papers, each examining slightly different processes/factors/variables, but is reported as one study as the data was obtained from the same population sample, thus leaving seventeen included studies.

Table 1 [INSERT HERE]

External Shame

A small number (*n*=4) of qualitative studies found that adults with ID frequently report having been subjected to numerous shaming experiences (Jahoda et al., 1988; Jahoda & Markova, 2004; Li et al., 2006), and were able to articulate that this often had significant impacts on their psychological and emotional well-being (Chen & Shu, 2012). This typically involved individuals with ID identifying that feeling 'bad' in daily life was linked to social rejection and a lack of social acceptance. However, studies reported that individuals with ID appear to cope with these experiences through actively rejecting the stigma attached to them (Jahoda et al., 1988) whilst feeling part of a minority group (Jahoda & Markova, 2004), and through various forms of avoidance (Jahoda & Markova, 2004; Chen & Shu, 2012).

Six studies explicitly utilised self-report measures pertaining to external shame, namely the Stigma Scale or Stigma Perception Questionnaire (SS/PSQ; Szivos, 1991) and the Perceived Stigma of Intellectual Disability Scale (PSID; Ali et al., 2008). The Stigma Scale (Szivos, 1991) is a ten-item measure that attempts to measure the perception and experiences of stigma/discrimination from others. The PSID (Ali et al., 2008) is also a ten-item measure of self-reported stigma that divides

into two sub-scales, one measuring discrimination and negative treatment by others (perceived discrimination), and the other measuring emotional reactions to discrimination.

Ali et al. (2015)[1] conducted a cross-sectional study involving 229 individuals with a mild to moderate ID, to investigate the relationship between self-reported experiences of stigma and numerous important health outcomes, including whether there was a relationship with psychological distress such as anxiety and depression. Utilising multiple linear regression analysis, results demonstrated that higher rates of self-reported stigma were associated with higher levels of psychological distress (regression coefficient = 0.94, $p < 0.01$) and lower quality of life (QoL). Psychological distress fully mediated the relationship between self-reported stigma and all but one of the other outcome variables. The relationship between self-reported stigma and all outcome variables remained unmodified when taking into account potential confounds such as age, gender, ethnicity, and severity of ID (regression coefficient = 0.95, $p = 0.01$). None of the sample had a diagnosed mental health problem, as this was an exclusion criteria for the study. Using the same sample, Ali et al. (2015)[2] found that those with moderate intellectual disabilities reported more experiences of having been

externally shamed, and that this was particularly so for individuals who were male and of an older age.

Four studies measured the relationship between external shame and subsequent self-esteem. Two studies (Dagnan & Waring, 2004; Paterson et al., 2012) utilised the adapted Rosenberg Self-esteem Scale (RSES; Rosenberg, 1965; adapted RSES; Dagnan & Sandhu, 1999), whilst the other two studies (Szivos-Bach, 1993; Abraham et al., 2002) utilised a composite self-esteem measure developed by Szivos-Bach (1993). All of these studies found that those individuals with ID who report being most aware (and experiencing higher levels) of shaming/stigmatisation from others have lower self-esteem.

Szivos-Bach (1993) found that those who had the greatest awareness of stigma and subsequent lowest self-esteem reported the highest levels of feeling inferior (i.e. feeling fundamentally different to others), and the lowest self-concept/self-efficacy (i.e. feeling the least likely to live up to their ideals and aspirations). This was supported by Dagnan and Waring (2004), who found that perceived stigma was strongly significantly correlated (r = 0.41, p <0.05) with perceived other–to-self negative evaluations (i.e. external shame). This was further associated with feeling fundamentally different (as measured by a subscale of the

PSQ), which in turn was positively associated with negative evaluative beliefs about the self.

Paterson et al. (2012) reported that only the negative self-esteem factor (r = 0.45, p < 0.01), and not the positive self-esteem factor, of the RSES was positively related to stigma. Further regression analysis revealed perceived stigma to be predictive of self-esteem (β = 0.31, p = 0.005). They suggested this may reflect that individuals with ID who are more likely to perceive stigma are thus more likely to feel bad about themselves (i.e. ashamed), and that the reverse is also true (i.e. feeling bad/ashamed about oneself leads one to perceive more stigma).

One other study involving participants with ID in a competitive employment setting also replicated the findings of higher perceptions of stigma being associated with lower self-esteem, and that higher levels of stigma were also associated with feelings of loneliness (Petrovski & Gleeson, 1997).

Using a novel experimental paradigm, Esdale et al. (2015) revealed that individuals with mild to moderate ID are potentially more likely to be sensitive to and distressed by criticism, when compared to adults without ID. This was characterised by significant differences ($\chi^2(1) = 22.33, p$ = 0.001) in the emotional response to criticism, with the ID

group more frequently reporting an internal negative emotional response (e.g. sad, depressed, down). These responses were noted to occur more frequently in the ID than non-ID groups across scenarios regarding performance ($\chi^2(1) = 3.75$, p = 0.053), popularity ($\chi^2(1) = 5.58$, p = 0.02), and autonomy ($\chi^2(1) = 8.64$, p = 0.003).

One other study (Garaigordobil & Pérez, 2007), that found lower self-concept and lower self-esteem in adults with mild to moderate ID than individuals without ID, reported significantly higher levels of interpersonal sensitivity (p = 0.01) in the ID group. Interpersonal sensitivity, as measured by the SCL-90-R (Derogatis et al., 1983), relates to feelings of shame, the tendency to feel inferior to others, and hypersensitivity to attitudes/opinions of others.

Consistent findings across these studies suggest that the higher the level of perceived or felt external shame, the higher the level of self-reported psychological distress. However, this in itself does not directly explain the mechanisms and reasons why some individuals do or do not develop significant psychological/emotional difficulties after experiencing such shaming social interactions. For this, we turn to a review of research studies that have explored internal processes of self-evaluation such as social comparison and self-criticism, which

relate more closely to the previously outlined concept of *internal shame*.

Internal Shame

Social Comparison

Social comparison can be conceptualised from an evolutionary perspective as an evaluation of one's social rank (Gilbert et al., 2000), processes associated with competitive motives to gain status and attractiveness in social groups (Gilbert et al., 1995). Social comparisons can be directed upwards, downwards, or laterally. Upwards comparisons are those where one compares oneself to someone in a more favourable or superior position, downward comparisons comprising those comparing oneself to others seen as inferior, and lateral comparisons being those with others who are considered similar/the same on a comparison dimension. All of these can serve different functions and differentially impact on one's emotions and self-esteem (Allan & Gilbert, 1995). Research in adult populations suggests that negative social comparison (i.e. feeling inferior) is highly related to shame, submissive behaviour, social anxiety, and depression (Gilbert et al., 2000).

Eight studies attempted to study the role of the process of social comparison(s), and its relationship between stigma and a number of important variables/outcomes pertaining to psychological distress and self-worth (e.g. levels of anxiety, depression, and self-esteem). The majority of these (*n*=5) utilised an adapted version of the Social Comparison Scale (SCS; Allan & Gilbert, 1995; Dagnan & Sandhu, 1999), which is a measure of one's relative social rank derived through comparing oneself to others across the domains of rank and achievement, social attractiveness, and group belonging. Lower scores indicate general feelings of inferiority and low rank self-perceptions.

Six studies found that when individuals with ID made negative (i.e. unfavourable) social comparisons, this was positively correlated/associated with higher levels of psychological distress, and negatively correlated with self-esteem (Dagnan & Sandhu, 1999; Dagnan & Waring, 2004; MacMahon & Jahoda, 2008; McGillivray & McCabe, 2007; Paterson et al., 2012; Szivos-Bach, 1993). Dagnan and Sandhu (1999) reported a medium to strong significant correlation between total social comparison score and depression (r = -.0.50, p < 0.001), whilst Paterson et al. (2012) also report similar effects for the relationship between total social comparison score and self-

esteem (r = 0.41 & 0.43, p = 0.01). The two studies that utilised clinical populations both found that those with ID who were clinically depressed made significantly more negative social comparisons than a non-depressed ID comparison group (MacMahon & Jahoda, 2008; McGillivray & McCabe, 2007), and that this reliably distinguished the two groups.

However, there was some discrepancy across studies in the type of social comparisons made. Three studies found that individuals with ID tend to make *downward* and/or *lateral* social comparisons, namely seeing themselves as the same or more favourably/superior than others with an intellectual disability, and that this was generally related to lower levels of psychological distress and higher self-esteem (Jahoda et al., 1988; Finlay & Lyons, 2000; Jahoda & Markova, 2004). One study (Paterson et al., 2012) reported that when individuals with ID compared themselves to fellow service users, if they rated themselves as more able/capable than their counterparts whilst reporting feeling part of the same group, this was correlated with higher levels of self-esteem (r = 0.4, p < 0.01). Equally, those with ID who saw themselves as more socially attractive and capable than comparison targets in the community also reported higher levels of self-esteem (r = 0.41,

$p < 0.01$), and a more positive view of self (Paterson et al., 2012).

When examining the *domains* in which social comparisons are made, four studies indicated that individuals with mild to moderate ID make more negative social comparisons (i.e. feel more inferior) on the domains of social attractiveness and achievement/capability (Dagnan & Sandhu, 1999; Dagnan & Waring, 2004; MacMahon & Jahoda, 2008; Paterson et al., 2012; Szivos-Bach, 1993). One study found that social comparisons in the domain of social attractiveness ($\beta = -0.32$, $p = 0.02$) and group belonging ($\beta = -0.29$, $p = 0.04$) significantly and independently predicted depression in a regression model (Dagan & Sandhu, 1999). One study utilising a clinical sample found that depressed individuals made more negative social comparisons on the dimensions of social attractiveness ($z = -3.17$, $p < 0.01$) and achievement ($z = -2.01$, $p < 0.05$) than their non-depressed matched counterparts (MacMahon & Jahoda, 2008). Additionally, one study reported that higher levels of stigma were related to social comparisons on the dimensions of social attractiveness ($r = 0.35$, $p < 0.05$) and capability ($r = 0.34$, $p < 0.05$) when individuals compared themselves to members of the community, but not similar others e.g. other service users/people with ID (Paterson et al., 2012).

Self-criticism and Self-evaluation

Self-criticism can be conceptualised as a harsh, judgmental relationship with and way of relating to oneself. Theories of self-criticism suggest that its development is related to how others have treated us, typically in response to being shamed, criticised and rejected by others (Irons et al., 2006; Shahar et al., 2015), and that it can serve various functions (Gilbert et al., 2004).

Four studies (Dagnan & Waring, 2004; Esdale et al., 2015; Hartley & Maclean, 2009; McGillivray & McCabe, 2007) investigated the potential role of the other salient components of internal shame, namely that of self-criticism and self-evaluative beliefs.

Using regression analyses, Dagnan and Waring (2004) found that experiences of stigma were highly predictive of negative evaluative beliefs about the self ($\beta = 0.55$, $p = 0.001$), which in turn predicted negative social comparisons ($\beta = -0.35$, $p = 0.04$). They found that whilst stigma was a significant predictor of social comparison on its own ($\beta = -0.42$, $p = 0.01$), this was mediated by negative evaluative beliefs.

In examining numerous potential risk factors associated with and the development of depression in adults with mild to

moderate ID, McGillivray and McCabe (2007) found that self-criticism was one of the most frequently reported indicators of and risk for depression. Self-criticism was self-reported more highly in the depressed group (68.8%) than both an 'at risk' group (39.6%) and a non-depressed group (3.6%). The same pattern was also observed for punishment feelings (depressed = 56.3%, 'at risk' = 25.1%, non-depressed = 3.6%), worthlessness (depressed = 56.3%, 'at risk' = 12.5%, non-depressed = 5.5%), and self-dislike (depressed = 39.6%, 'at risk' = 12.5%, non-depressed = 0%). Further support for the role of self-criticism was evidenced in their multiple regression analysis, which found that negative automatic thoughts (as measured by the ATQ) had the greatest significant impact on depression scores (β = 0.55). Analyses also highlighted infrequent (β = -0.21) and poor quality social support (β = 0.22) as significant predictors of depression scores, whilst social comparison did not contribute significantly (McGillivray & McCabe et al., 2007).

In the Esdale et al. (2015) study, whilst the study design could not allow for more detailed analyses, content analysis revealed that the ID group managed to identify an equivalent number of self-derogatory responses to perceived/imagined criticism from others as a non-ID group. However, the ID group

were significantly more likely to focus the blame for criticism internally ($\chi^2(1) = 22.33$, p = 0.001). Furthermore, the ID group were significantly more likely to believe the criticism they received ($\chi^2(1) = 3.87$, p = 0.049), particularly in the domain of popularity ($\chi^2(1) = 13.33$, p < 0.001).

One other study (Hartley & Maclean, 2009) also reported that depressed individuals with ID were significantly more self-blaming for negative events than a matched non-depressed comparison group, as evidenced by an elevated negative attributional style for negative and stressful social interactions.

General Criticisms/Limitations of Research

One of the major limitations of the studies lies in the fact that the majority of studies are cross-sectional in nature, and therefore any relationships that are found cannot be directly indicative of causality. Some of the sample sizes were relatively small, and the heterogeneity of samples makes it difficult to generalise findings as representative of the majority of people with mild to moderate ID. The vast majority of studies (*n*=11) recruited individuals from settings such as day/resource centres or residential settings, and thus may not be representative of individuals with ID in other community

settings (e.g. competitive and/or voluntary employment, supported living in the community).

The majority of studies failed to investigate other potential factors that may act as mediators and moderators of both shame and psychological distress. These may include age, gender, race, socioeconomic status, level of social support, sexuality, presentation of challenging behaviour, and the degree, nature, and 'visibility' of intellectual disability. Only three studies investigated the association and potential influence of these sociodemographic variables (Ali et al., 2015[1&2]) on these domains, or specifically age and gender (Dagnan & Waring, 2004; Paterson et al., 2012) on scale scores of social comparative/self-evaluative components.

Some of the limitations of the identified studies relate to the measurement, and specific elements and dimensions, of social comparison(s). Many of the studies fail to report the target group that individuals make comparisons to (e.g. whether this is fellow individuals with ID, or members of the community in general). At least two studies demonstrated that this makes a potentially significant difference on the types social comparisons made (MacMahon & Jahoda, 2008; Paterson et al., 2012), and the subsequent impact this can have on self-esteem and psychological/emotional distress. Secondly, it is

also important to distinguish which domains of self individuals are making social comparisons on (e.g. social attractiveness and autonomy), as these will like equally impact on subsequent psychological distress and self-worth. One study did not explicitly report this, rather just providing an overall social comparison score (McGillivray & McCabe, 2007). Thirdly, the particular social circumstances of the participants used, such as living in residential and community settings, may also play a significant impact in terms of who individuals with ID compare themselves to, and on what domains. This varied significantly throughout the studies, and may have been a significant influencing factor on individuals' experience of shame.

The validity and reliability of some of the measures for this population is also somewhat questionable. Some of the measures utilised in studies are those that were validated on child populations, had been adapted/modified, and/or had not been properly validated on ID populations (e.g. McGillivray & McCabe, 2007). Additionally, the outcome measures and/or methods utilised to assess psychological distress and self-worth varied across studies, which makes it difficult to generalise findings due to the differing psychometric properties and validity of each measure and procedure. The

adapted Rosenberg Self Esteem Scale (Rosenberg, 1965), which was widely used in many of the studies to assess individual's self-esteem, has been seriously questioned as a reliable measure for use in this population, on the grounds of questionable internal reliability and poor criterion validity (Davis et al., 2009). The RSES also contains some social comparative items/components, which may confound findings when used alongside the Social Comparison Scale. This may explain why in some studies there was no observed moderating impact of social comparison between stigma and self-esteem when regression analysis was conducted, as has had been predicted (Paterson et al., 2012). As self-esteem and social comparison share some conceptual similarities, this may explain why in studies that utilise multiple regression analyses, social comparison is sometimes not found to be a significant predictor (McGillivray & McCabe, 2007)

There are also some potential issues with the varying stigma measures used. Varying levels of reliability and validity have been reported for the stigma measures across studies, including differing factor structures (Abraham et al., 2002; Werner et al., 2012). Both stigma measures used in the identified studies potentially measure different aspects of shame and load them into one overall score of stigma

perception. Whilst they are helpful measures, it makes it especially difficult to distinguish between aspects of external and internal shame, and the impact that this may have on different facets of psychological distress and functioning. Additionally, these measures do not explicitly measure who has done the shaming (i.e. peers, family, general public), which may provide important information for effective formulation and intervention.

Many of the studies identified processes through which individuals with ID engaged in social comparative and evaluative processes that helped mitigate psychological distress, maintain their self-esteem, not internalise shaming experiences, and/or thus demonstrate adaptive and resilient responses to such experiences. However, there was little explicit investigation, exploration or measurement of the processes, mechanisms, factors and contexts that may have contributed to these differing responses.

There is a distinct lack of research with clinical populations, which would helpfully further elucidate to the extent shame and shame-based processes play in mental health issues in this population. The majority of studies were conducted with non-clinical ID populations, so it is hard to generalise these findings to clinical ID populations. However, it may be safe to assume if

(milder) shame-based issues are evident and prevalent in non-clinical populations, these are even more likely to be prevalent in clinical ID populations, which is supported by a limited number of studies included in this review (McGillivray & McCabe, 2007; MacMahon & Jahoda, 2008; Hartley & Maclean, 2009).

Discussion

Findings from this review appear to support the notion that for a significant number of individuals with mild to moderate ID, shaming (stigmatising) experiences may significantly impact on their sense of self, self-to-self relating (i.e. become self-critical), the types of social comparisons they make with salient others, and subsequent self-worth and emotional well-being. A handful of studies reported findings inconsistent with these results, where aspects of shame did not appear to negatively impact on self-concept (Jahoda et al., 1988) or result in unfavourable social comparisons (Jahoda & Markova, 2004). A small number of studies (*n*=2) also reported relatively high levels of self-esteem in their participants in the face of apparent (external) shame (Abrahams et al., 2002; Paterson et al., 2012).

In synthesising the results, we draw on Gilbert's (2002) evolutionary biopsychosocial model of shame (Figure 2, see Appendix 2) as a potentially helpful explanatory model and framework.

Figure 2 [INSERT HERE]

A number of the studies not surprisingly suggest that experiencing external shame appears in and of itself to elicit psychological distress, in engendering anxiety, depression and lowering self-esteem (e.g. Ali et al., 2015; Esdale et al., 2015; Paterson et al., 2012). This is not surprising, given that shame signals threat(s) to the (social) self, and corresponding biobehavioural responses to react to such threats, to prevent further harm or complete social rejection (Dickerson et al., 2009). This would appear to suggest that a significant number of individuals with ID may feel unsafe in the world and their social contexts, due to previous and current experiences of seeing others as potentially rejecting or hostile, which activates a range of defensive processes such as anxiety and depression to avoid or cope with such actual or anticipated shame experiences (Gilbert, 1989, 2005).

Results from the studies in this review generally report significant relationships between stigma and negative evaluative beliefs about the self (Dagnan & Waring, 2004), heightened self-criticism (Esdale et al., 2015; McGillivray & McCabe, 2007) and negative self-attributions (Hartley & Maclean, 2009), and lower negative self-concept (Garaigordobil & Pérez, 2007). This could be explained by the process of the *internalisation* of shame following experiences of external shaming (Gilbert, 2003). One potential conceptual issue relates to whether these self-evaluative concepts are indeed distinct concepts and processes, or tapping into a more global sense of lower self-worth. Social mentality theory (Gilbert, 2005) would suggest that these processes are part of competitive social rank mentalities which are activated when one feels threatened and insecure. However, these issues are beyond the scope of this review, and require further investigation.

Additionally, some of these studies suggested some individuals with ID have a heightened sensitivity to, and self-blame for, social criticism (Esdale et al., 2015; Dagnan & Waring, 2004). This may reflect a sensitivity to social put-down, whereby negative social experiences (e.g. being criticised, rejected, bullied, subordinated) result in heightened sensitivity to

criticism and social put-down from others (Gilbert & Miles, 2000, Gilbert et al., 2006). Sensitivity to social-put down and subsequent self-blame for receiving criticism from others has been shown to be positively associated with shame, anxiety and depression in non-ID adult populations (Gilbert & Miles, 2000; Gilbert et al., 2006). Indeed, there is some support for this from another study in this review, which found that individuals with ID are more interpersonally sensitive than those without ID (Garaigordobil & Pérez, 2007). In short, in many cases it is likely that some individuals internally relate to themselves in the same critical manner that others have treated them, particularly when faced with challenges, setbacks and failures, and that they subsequently expect others to think of and treat them in a similarly negative manner. Thus, they may shame themselves, which further negatively impacts on their psychological well-being, leaving them vulnerable to depression, anxiety, and other mental health difficulties. This is supported by research in non-ID adult populations, which demonstrates that self-criticism typically develops out of being treated negatively by others and is reliably associated with vulnerability to increased psychopathology (Irons et al., 2006; Stuewig & McCloskey, 2005).

It appears to be a similar story in regards to social comparison. Although mixed findings were reported, a large majority of studies included in this review reported that negative social comparisons were related to higher levels of psychological distress and lower self-esteem (Dagnan & Sandhu, 1999; Dagnan & Waring, 2004; MacMahon & Jahoda, 2008; McGillivray & McCabe, 2007; Paterson et al., 2012; Szivos-Bach, 1993). There was some suggestion that negative social comparisons are particularly elevated in adults with ID who are depressed as compared to those ID individuals who are not depressed (MacMahon & Jahoda, 2008; McGillivray & McCabe, 2007). Results would suggest that it is in the domains of social attractiveness and capability/ability where social comparisons are particularly salient for adults with ID, in that individuals with ID are more likely to experience shame in relation to these domains of self and social roles. The findings relating to social comparison are consistent with evolutionary social rank theory that has linked unfavourable social comparison(s) to shame, social anxiety, depression, and submissive behaviour in non-ID adult populations (Gilbert, 1997, 2000; Gilbert et al., 2002; Allan & Gilbert, 1997). However, as this is a narrative review, it is not possible to be clear about causal theories such as these. This is due to the previously outlined limitations in the studies, and the fact that

the studies were not specifically designed to test such theories in relation to adults with ID.

Whilst the above model can help to make sense of how and why shame and shame-based processes develop and operate in people with ID, it does not explicitly explain how shame is mitigated against or adaptively responded to. Research with adult populations suggests that protection against shame and subsequent psychopathology is related to past and current affiliative relationships with others that lead to experiences of social safeness, through being able to access and use social relationships as a source of soothing and safeness (Matos et al., 2015). At least one of the studies in this review suggested that for depressed individuals with ID that appear to experience shame-based difficulties (e.g. self-criticism, negative social comparison), lack of social connectedness and emotional support was evident (McGillivray & McCabe, 2007). Thus, the degree to which individuals feel emotionally connected and supported may potentially be significant factors in ameliorating shame and shame-based difficulties.

Equally, many of the studies appear to suggest that individuals who engage in more downward or lateral social comparisons may experience less shame, as evidenced by higher levels of self-esteem when they engage in these more 'positive'

comparisons (Jahoda et al., 1988; Finlay & Lyons, 2000; Jahoda & Markova, 2004; Paterson et al., 2012), and elevated appraisals of their self-concept (Li et al., 2006). However, it remains open to debate as to whether this is a solely positively adaptive process in maintaining/sustaining one's self esteem, or in some instances as a form defence against shame through denial (Allan & Gilbert, 1995; Sinason, 1992). There is evidence that both upward or downward social comparisons can reduce prosocial behaviour towards and empathy for others (Yip & Kelly, 2013), lead to behavioural avoidance of others and social distancing (Chen & Shu, 2012), and to other forms of less prosocial behaviour such as derogating against similar others as a way of maintaining one's self-esteem (Szivos-Bach, 1993). Only one study in this review reported evidence relating to this more externalising, humiliating response to feeling shamed in individuals with ID (Szivos-Bach, 1993). Other studies not included in this review that have examined aggressive challenging behaviours in individuals with ID have suggested that this may be in response to being or feeling shamed in some way (Larkin et al., 2012). Furthermore, there is the wider issue that some individuals with ID are not aware or do not see themselves as having an ID, and therefore do not internalise the shame/stigma that can be associated with the label (Cunningham & Glenn, 2004).

Conclusion

This review and synthesis suggests that shame and shame-based processes may play a potentially significant role in the development and maintenance of psychological distress and mental health issues in some individuals with mild to moderate ID. Not surprisingly, as much of the previous research on stigma has suggested, there appears to be a direct relationship between experiences of being shamed and believing that others perceive the self negatively (*external* shame), and the development/experience of significant psychological distress in adult individuals with mild to moderate ID. However, the significance of these findings is somewhat limited by the cross-sectional nature of the vast majority of the included studies.

Furthermore, this review provides further support for the notion that these individuals also experience difficulties relating to *internal* shame, in terms of becoming prone to feeling inferior to others and 'bad' about the self. This includes engaging in shame-based self-evaluative processes such as negative social comparison and self-criticism, much in the same manner that adults without an ID also engage in these processes (Dagnan & Sandhu, 1999; Dagnan & Waring, 2004; Esdale et al., 2015). Similarly, there is no reason to assume

that these psychological/emotional processes are not amenable to psychological intervention as in non-ID populations, as demonstrated in recent therapy process and intervention studies (Pert et al., 2013; Idusohan-Moizer et al., 2015).

Although the evidence reviewed, and thus the scope of the review, is somewhat limited, there are several implications that potentially arise. In terms of implications for further research, more research is required into the potential role of shame in mental health issues in individuals with ID, possibly with the development/adaptation and validation of existing shame measures such as the Other as Shamer Scale (Goss et al., 1994) for this population. Such recommendations for the development of similar, stigma-based measures have already been made elsewhere (Werner et al., 2012). Furthermore, more research is likely required into the various factors and processes that mitigate/ameliorate shame in this population.

In terms of potential clinical implications, clinicians need to be mindful of shame-based issues when assessing and treating people with ID, and to more actively assess for and include these in their formulations and treatment plans. Accordingly, clinicians may wish to develop and adapt psychological interventions that explicitly work with and reduce shame

(external and internal), unhelpful social comparisons, and self-criticism in this population. Interventions that explicitly cultivate self-compassion as an antidote to shame and self-criticism may be promising options. Self-compassion has been shown in general adult populations to be associated with reduced psychopathology (MacBeth & Gumley, 2012), reduced shame and self-criticism and (Gilbert & Procter, 2006), and a more stable sense of self-worth and predictor of emotional well-being than self-esteem (Neff & Vonk, 2009).

Compassion Focused Therapy (CFT; Gilbert, 2005, 2009, 2010) is one such promising approach, as it was originally specifically developed for individuals with mental health difficulties characterised by high shame and self-criticism. CFT explicitly targets the development of affiliative emotion that helps to engage with and regulate difficult (threat-based) emotions, and tone up positive emotions of safeness, contentment, and well-being. Given that recent research indicates that individuals with ID respond to affiliative signals that positively impact on their sense of self and well-being (Esdale et al., 2015), helping them cultivate self-compassion could be a powerful resource to regulate shame, reduce and cope with distress, and improve emotional well-being and resilience. There is growing evidence for the effectiveness of CFT for a

range of psychological difficulties in people without an ID (Leaviss & Uttley, 2015; Beaumont & Hollins Martin, 2015). However, there is currently a lack of research into the use of CFT with people with ID. Hence, this is an area that warrants further study.

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Conflict of Interest

The author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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APPENDIX 1

Table 1 Overview of studies examining shame/shame-based process in individuals with a mild to moderate Intellectual Disability

Study	Country	Research Method/Design	Sample Size & Characteristics	Measures & Procedures	Aspect(s) of Shame measured	Main Findings	Limitations
Abraham et al. (2002)	UK	Cross-sectional	50 (22 male, 28 female; age range 23-65)	Stigma Scale, Self-esteem measure (Szivos-Bach, 1993)	External	Self-esteem negatively correlated with stigma; self-esteem generally high; half of sample scored lowest on aspects of stigma (reputation & stranger concern)	Participants recruited from two day centres, limited generalisability (some participants living at home whilst others in supported living), IQ not formally assessed
Ali et al. (2015)[1&2]	UK	Cross-sectional	229 (120 male, 109 female)	Perceived Stigma of Intellectual Disability Scale, CORE 14-item version, QofL Questionnaire	External	Self-reported stigma significantly positively associated with psychological distress (including when adjusted for potential confounds), including both subscales of PSID ; psychological distress fully mediated relationship between self-reported stigma and other outcome variables (e.g. Quality of Life); moderate ID, age, and gender (male) related to severity of self-reported stigma	IQ not formally measured, all outcome measures self-report, excluded participants with a diagnosed mental health problem

Study	Country	Research Method/Design	Sample Size & Characteristics	Measures & Procedures	Aspect(s) of Shame measured	Main Findings	Limitations
Chen & Shu (2012)	Taiwan	Qualitative	14 (8 male, 6 female; age range 17-22)	Semi-structured interviews	External & Internal	Participants aware of sources of stigma; evidence they internalised stigma through viewing themselves as 'not good', 'odd', 'sick', and 'troublemakers'; utilised avoidance, isolation, and self-promotion as way of coping	Small sample size, limited generalisability (participants were students recruited from one higher special educational establishment), excluded those with ASD diagnoses
Dagnan & Sandhu (1999)	UK	Cross-sectional	43 (25 male, 18 female), mean age 35.1 years	Social Comparison Scale (SCS), Rosenberg Self-esteem Scale (RSES), Zung Depression Scale (Zung, 1965)	Internal	Social comparison and self-esteem total scores negatively associated with depression; positive self-esteem, and social comparison on dimensions of social attractiveness and group belonging negatively related to depression	Overlap of self-esteem and social comparison measures may confound analysis, no control group for comparison or to take account of confounding variables
Dagnan & Waring (2004)	UK	Cross-sectional	39 (21 males, 18 females), age range 23-65 years	Stigma Scale, Evaluative Beliefs Scale, Social Comparison Scale (SCS)	External & Internal	Total stigma score predicted negative evaluative beliefs, in turn predicting social comparison; relationship between negative self-evaluations and social attractiveness dimension of social comparison, stigma directly impacted on social comparison	Cannot determine causality due to cross-sectional nature, internal reliability for SCS in study was low

Study	Country	Research Method/Design	Sample Size & Characteristics	Measures & Procedures	Aspect(s) of Shame measured	Main Findings	Limitations
						processes, mediated by evaluative beliefs	
Esdale at el. (2015)	UK	Between-groups	20 with ID (12 male, 8 female; age range 18-54 years), control group of 20 adults without ID (9 male, 11 female; age range 18-63 years)	Glasgow Depression Scale for people with a Learning Disability (GDS-LD), Praise and Criticism Task (PACT)	External & Internal	ID group more likely to believe and be distressed by criticism and focus blame for criticism internally, but also more likely to believe praise and experience related positive affect	Small sample size, experimental paradigm, no assessment/measurement of perceived stigma (external shame)
Finlay & Lions (2000)	UK	Qualitative	33 (13 male, 20 female; age range 18-65)	Semi-structured interviews	Internal	Tendency to make lateral & downward social comparisons with others with ID (viewing themselves as the same or better)	No assessment/ exploration of experiences of stigma (external shame)
Garaigordobil & Pérez (2007)	Spain	Between-groups	42 with ID (33 male, 9 female; age range 19-40 years), 128 without ID (74 male, 54 female; age range 12-65 years)	Rosenberg Self-esteem Scale (RSES), Adult & Adolescent Self-concept Adjective checklist (LAEA), Revised Symptom Checklist (SCR-90)	Internal	Significantly lower self-concept and self-esteem in ID group than non-ID comparison; significantly higher psychopathological symptoms in ID vs. non-ID group, including highly significant difference in levels of interpersonal sensitivity	No measure of perceived stigma (external shame) utilised, unbalanced sample sizes for comparison
Hartley & Maclean (2009)	USA	Between-groups	47 depressed (24 male, 23 female;	Causal Attribution question (assessed	Internal	Significantly higher frequency of negative attributions in depressed	No assessment/measure of perceived stigma

Study	Country	Research Method/Design	Sample Size & Characteristics	Measures & Procedures	Aspect(s) of Shame measured	Main Findings	Limitations
			mean age 42.62) vs. 47 non-depressed (24 male, 23 female; mean age 41.74)	independently by two separate parties across domains of Internality, Stability, & Globality); also assessed frequency & severity of negative social interactions, and Coping strategies		than non-depressed group for stressful/negative events and social interactions; significantly more avoidant coping strategies reported in depressed vs. non-depressed group	(external shame) utilised, potential confounds as some participants in both groups had non-depressive psychiatric diagnosis
Jahoda et al. (1988)	UK	Qualitative	12 (5 male, 7 female), age range 21-40 years	Semi-structured interviews	External	All participants reported awareness of stigma; 25% of participants identified themselves as 'essentially different', majority (75%) identified themselves as 'essentially the same' as others	Small sample size, method of qualitative analysis (e.g. coding and identification of themes) not reported
Jahoda & Markova (2004)	UK	Qualitative	10 community group (3 male, 7 female; age range 20-40), 18 hospital group (15 male, 3 female; age range 20-55)	Semi-structured interviews	External & Internal	All participants aware of being stigmatized (e.g. social rejection, humiliation, discrimination, prejudice) in day-to-day lives, and aware of stigma associated with ID; majority made downward social comparisons with peers	Small sample size, validity & reliability of coding frame for data not assessed or verified
Li et al. (2006)	China	Qualitative	135 with mild	Semi-structured	External	Lack of social acceptance from others	Cultural variables (e.g.

Study	Country	Research Method/Design	Sample Size & Characteristics	Measures & Procedures	Aspect(s) of Shame measured	Main Findings	Limitations
			ID(65 male, 70 female; age-range 18-52 years) vs. 146 non-ID adults (age range 20-55)	interviews using Chinese version of Adult Source of Self-esteem Inventory (ASSEI; Elovson & Fleming, 1989)		(friends/peers/co-workers/general public) contributed to 'bad' feeling an day-to-day life; majority of participants reported more positive/elevated self-concept and self-esteem compared to non-ID comparison group	collectivist values) may have been defining influence & not controlled for, generalisabiltiy of sample due to majority being in special educational settings
MacMahon & Jahoda (2008)	UK	Between-groups	18 depressed vs. 18 non-depressed	Glasgow Depression Scale for people with a Learning Disability (GDS-LD), Sung Depression Scale, Rosenberg Self-Esteem Scale (RSES), Social Comparison Scale (SCS)	Internal	Significantly higher level of negative social comparisons reported in depressed vs. non-depressed group; lower levels of self-esteem in depressed vs. non-depressed group (low self-esteem & depression highly correlated); positive social comparisons more salient for non-depressed group	Small sample size, groups not well matched, limited generalisability due to specific social circumstances
McGillivray & McCabe (2007)	Australia	Between-groups	151 (83 male, 68 female; age range 19-68 years)	Beck Depression Inventory II (BDI-II), Reynolds Adolescent Depression Scale (RADS), Social Comparison Scale (SCS), Rosenberg Self-	Internal	Significant difference on social comparison and self-esteem (significantly lower), and negative automatic thoughts (significantly higher) between individuals with and without depression symptoms; levels of self-criticism and self-dislike	No measures relating to perceived stigma (external shame) utilised, use of modified measures with unsubstantiated psychometric validity/integrity

Study	Country	Research Method/Design	Sample Size & Characteristics	Measures & Procedures	Aspect(s) of Shame measured	Main Findings	Limitations
				esteem Scale (RSES), Automatic Thoughts Questionnaire-Revised (ATQ-R)		reported with greater frequency in depressed vs. non-depressed group	
Paterson et al. (2012)	UK	Cross-sectional	43 (18 male, 25 female), age range 20-66	Stigma Scale, Social Comparison Scale (SCS), Rosenberg Self-esteem Scale (RSES)	External & Internal	Greater perception of stigma related to negative social comparisons and lower self-esteem (only negative self-esteem factor related to stigma)	Relatively small sample size, overlap of self-esteem and social comparison measures may confound analysis
Petrovski & Gleeson (1997)	Australia	Cross-sectional (mixed methods)	31 (15 male, 16 female), aged range 18-41	Stigma Scale, Self-esteem measure (Social Comparisons test; Szivos-Bach, 1993); semi-structured interviews	External	Negative correlation between stigma & self-esteem, 47% reported feeling 'different' & not comfortable feeling this way; stigma also associated with loneliness	Small sample size only drawn from one source (one vocational agency)
Szivos-Bach (1993)	UK	Cross-sectional	50 (30 male, 20 female), age-range 16-21	Stigma Scale, Self-esteem measure (Social Comparisons test) Aspirations & Expectations	External & Internal	Higher levels of stigma associated (negatively correlated) with lower levels of self-esteem; slight tendency towards downward social comparisons; participants with lowest self-esteem reported poorer opinions of friends and more loneliness	Relatively small sample, limited generalisability due to where sample drawn from (further educational establishments), potential confounds with self-esteem measures

APPENDIX 2

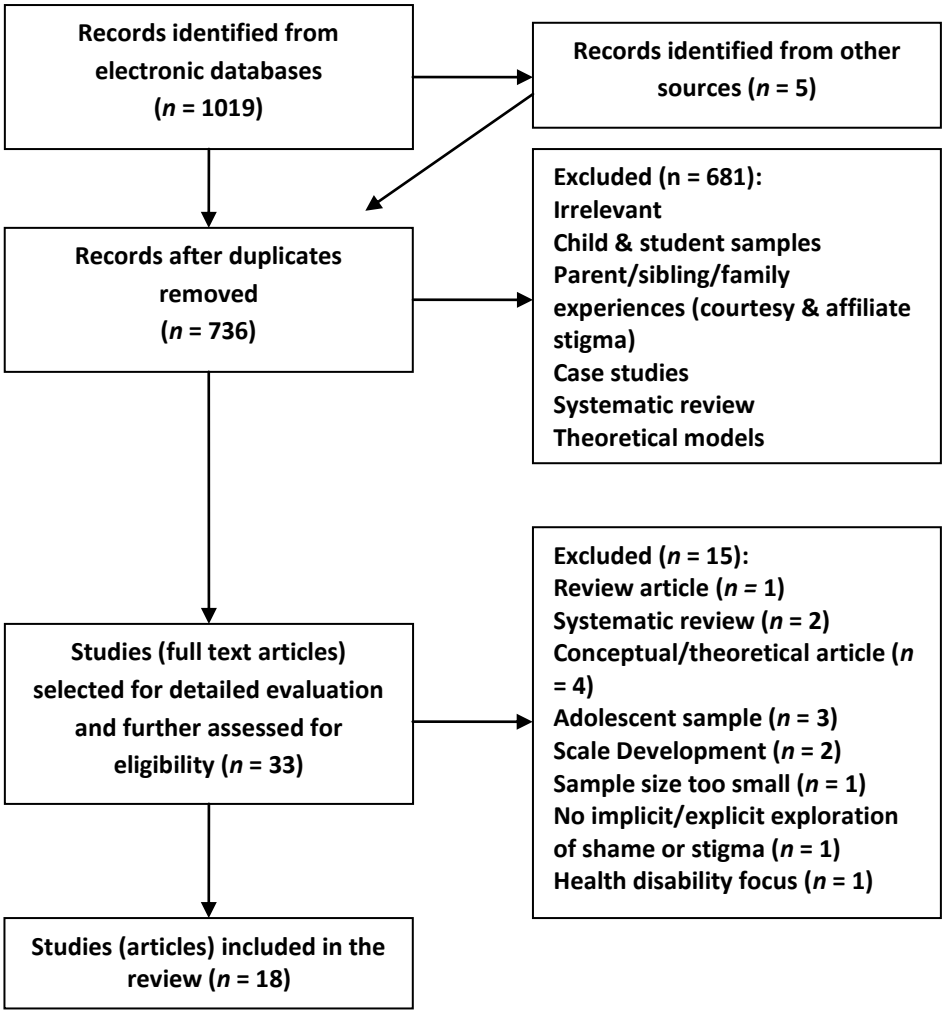

Figure 1 Flow diagram of study selection process

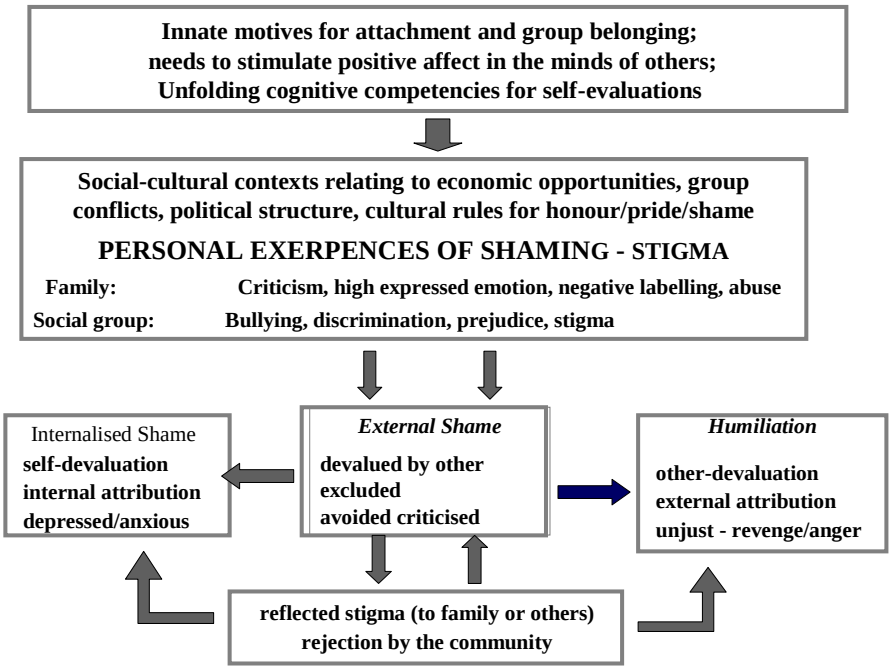

Figure 2 Evolutionary and biopsychosocial model of shame (adapted from Gilbert, 2002)

SECTION 3: Empirical paper

“Finding the person you really are...on the inside”: A feasibility study of adapted group Compassion Focused Therapy for adults with intellectual disabilities (CFT-ID)

Journal of Intellectual Disabilities (JOID) Submission Guidelines

The aim of the journal is to publish original research or original contributions to the existing literature on intellectual disabilities.

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“Finding the person you really are...on the inside”: A feasibility study of adapted group Compassion Focused Therapy for adults with intellectual disabilities (CFT-ID)

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Abstract

This study utilised a mixed methods approach to examine the feasibility and acceptability of group Compassion Focused Therapy for adults with Intellectual Disabilities (CFT-ID). Six participants with mild ID participated in six sessions of group CFT, specifically adapted for adults with ID. Session-by-session feasibility and acceptability measures suggested that participants understood the group content and process, and experienced group sessions and experiential practices as helpful and enjoyable. Thematic analysis of focus groups identified four themes relating to (1) Motivations for attending; (2) Direct experiences of the group; (3) Initial difficulties in being self-compassionate; and (4) Positive emotional changes. Pre and post-group outcome measures indicated significant increases in self-compassion, and significant reductions in both self-criticism and unfavourable social comparisons. Results suggest that CFT can be adapted for individuals with ID, and provides preliminary evidence that people with ID and psychological difficulties may experience a number of benefits from this group intervention.

Keywords

Compassion, compassion focused therapy (CFT), intellectual disability, self-criticism, shame

Introduction

People with Intellectual Disabilities (ID) are often exposed to, and have to contend with, experiences of social rejection, exclusion, discrimination and stigmatisation (Ali et al., 2012; Ditchman, et al., 2013; Werner, 2015). Growing evidence suggests these experiences significantly negatively impact on a number of psychological and emotional processes, such as the internalisation of stigma known as self-stigma (Ali et al., 2012), and the development and maintenance of psychological distress in adults with ID (Ali et al., 2012, 2015). Stigma processes can be helpfully conceptualised through the lens of *shame*. Gilbert's (1997, 1998, 2002) evolutionary biopsychosocial model of shame consists of two separate but over-lapping components. *External shame* relates to experiencing oneself as living negatively (e.g. as bad, unattractive, flawed, defective) in the minds of others, feeling rejected and vulnerable to attack, making the social world unsafe and thus activating a range of defensive strategies (e.g. anxiety, depression) to deal with these perceptions. *Internal shame* relates to an internal self-focus, negative self-evaluations (e.g. self-criticism) and self-directed (shame) affects, where the self is evaluated as inadequate, flawed or bad.

The role of shame in the development and maintenance of psychological distress in those with ID is relatively neglected and overlooked, and not always specifically

targeted in interventions. Research indicates that some individuals with mild to moderate ID experience their 'disability' as a significant stressor, particularly the aspect of being seen as 'disabled' by the general public (Bramston et al., 1999). Many individuals with ID engage in negative social comparisons with others that lead to a sense of shame and subsequent mental health difficulties such as anxiety and depression (Dagnan & Sandhu, 1999; Dagnan & Waring, 2004), particularly through internalised shame (i.e. self-stigma) that results in negative self-evaluations and self-criticism (Ali et al., 2012; Dagnan & Waring, 2004; Esdale et al., 2015). Perception of stigma in adults with ID has been linked to negative social comparisons, subsequent depression and low self-esteem (MacMahon & Mahoda, 2008; Paterson et al., 2012). Recent research suggests that individuals with ID are more likely to believe and be distressed by (social) criticism than non-ID controls (Esdale et al., 2015). Group-analytic research has also identified shame, rejection, and grief as a common themes among individuals with mild ID (O'Connor, 2001), seemingly driven by the desire to fit in and be 'normal', and not be seen as having an ID.

Such research suggests that developing and adapting psychological interventions that explicitly and directly work with shame (external and internal) may be a promising avenue in reducing psychological distress and improving the well-being of individuals with ID. One potential therapeutic avenue as an antidote to shame and self-criticism is

to focus on helping people cultivate *compassion* towards the self and others (Gilbert, 2009, 2010; Neff, 2003a; Hofmann et al., 2011).

Compassion Focused Therapy (CFT; Gilbert, 2005, 2009, 2010) is one such promising approach, as it was specifically developed for people with mental health difficulties characterised by high shame and self-criticism. CFT focuses on helping people access and stimulate affiliative motives, emotions and competencies underpinning compassion that play important roles in threat regulation, well-being, and prosocial behaviour (Gilbert, 2014, 2015). Research indicates that compassion training can have wide-ranging physiological and psychological benefits, including changes at a neural and emotional level (Klimecki et al., 2014; Weng et al., 2013, Jazaieri et al., 2013), and thus is a trainable skill. This is likely enhanced in a group setting, as central to CFT is the creation of affiliative contexts to share, de-shame, validate, soothe, and encourage (Bates, 2005).

There is growing evidence for the effectiveness of CFT for a range of psychological difficulties in people without ID (Leaviss & Uttley, 2015; Beaumont & Hollins Martin, 2015). CFT has been shown to be feasible, acceptable and efficacious in a group format for individuals with wide-ranging and complex mental health difficulties (Gilbert & Procter, 2006; Judge et al., 2012; Lucre & Corten, 2013), and when adapted into briefer

group therapies (Heriot-Maitland et al., 2014). Group-based CFT has been shown to reduce shame, self-criticism, negative social comparisons, depression and anxiety in clinical populations (Gilbert & Procter, 2006; Judge et al., 2012; Lucre & Corten, 2012).

Group interventions have been developed and successfully adapted for individuals with ID (Rossiter et al., 2016), demonstrating effectiveness in reducing anxiety (Idusohan-Moizer et al., 2015), depression (McCabe et al., 2006), and problematic anger (Rose et al., 2000, 2005). In terms of compassion-based group interventions, one study has attempted to teach self-compassion to adult individuals with ID with recurrent depression and anxiety, but within the context of an adapted Mindfulness-Based Cognitive Therapy (MBCT) group intervention (Idusohan-Moizer et al., 2015). Whilst this resulted in significant increases in compassion for self and other, and reduced anxiety and depression, compassion was not the primary focus of the intervention. Hence, it is not possible to tease out the specific effects of the self-compassion component of this intervention.

To date, no known study has formally adapted CFT and related practices of Compassionate Mind Training (CMT; Gilbert & Irons, 2005; Gilbert & Procter, 2006) for individuals with ID, and/or investigated whether this is feasible and acceptable in a group format for this population.

Aims

The main aim of this study is to preliminarily investigate and explore whether an adapted CFT group intervention is feasible and acceptable for adults with ID who have concurrent mental health issues. Given that this is the first account of adapting and delivering a CFT group for individuals with ID, outcome data centres largely around session-by-session self-reports of participants perceived understanding and acceptability, and qualitative data regarding people's experiences of and within the group. Supplementary quantitative outcome data regarding effects on levels of self-compassion, psychological distress, and psychological well-being are also provided as initial exploration around potential efficacy of this adapted intervention.

Method

Recruitment procedure

Participants were recruited from NHS Community Learning Disabilities teams in North Wales. The nature and aims of the study were discussed within appropriate multidisciplinary team meetings, and team members were encouraged to identify and refer potentially suitable candidates that met the inclusion criteria. Referral packs

were also left for team members as both reminders of inclusion/exclusion criteria, and participant information sheets were provisionally shared with potentially interested participants.

The principal inclusion criteria were as follows: (1) a diagnosis of an Intellectual Disability; (2) aged 18+ (no upper age limit); (3) significant psychological distress, indicated by minimum score of 13[1] on the relevant index of the Psychological Therapies Outcome Scale for Intellectual Disabilities (Vlissides et al., in press); (4) accompanying self-criticism (as indicated by appropriate measures and informal behavioural observations); and (5) participants had to demonstrate the capacity to consent (as formally assessed in the pre-group assessment process). Exclusion criteria comprised of: (1) currently experiencing psychosis or mania; and (2) lack of capacity to understand the nature of participating in the research.

Participants

Nine participants were referred as potentially suitable candidates for the group. Two of these individuals were subsequently not assessed, due to one individual being in

[1] Equivalent to mean total score on Brief Symptom Inventory for mild ID with Axis 1 diagnoses (Wieland et al., 2012)

crisis at the time of referral, and the other being referred too late to be able to undergo the pre-assessment process. Accordingly, seven individuals underwent the pre-group assessment process, with all meeting the inclusion criteria for the study. One of these individuals subsequently did not attend any of the group sessions, and was thus not included in the study.

The mean age of the six participants included in the study was 38.5 years (*SD* = 15.6), consisting of four females (67%) and two males. All participants had previously been formally assessed for the presence of an Intellectual Disability, with all diagnosed as having mild ID (i.e. IQ between 51 and 70). All participants had a documented history of mental health issues that included anxiety (*n* = 1), depression (*n* = 1), or mixed anxiety and depression (*n* = 4).

Two rounds of the groups ran consecutively on one site, in order to recruit a sufficient number of participants after receiving a small number of referrals for the first group. Participants were given a choice as to whether they wished to be accompanied by a supporter/carer. Group 1 consisted of three participants (2 female, 1 male), one of whom was accompanied by a support worker for two sessions. Group 2 consisted of three participants (2 female, 1 male), all of whom were accompanied by support workers for the entirety of the group.

Methods of evaluation

This study utilised a mixed methods design combining quantitative and qualitative measures. Participants completed three outcome measures during the pre-group assessment process, and the same measures 2-4 weeks after the end of the intervention. The principal investigator assisted all participants in completing these measures.

CFT-ID Session Feasibility and Acceptability Measure. This measure was designed by the project team as a descriptive measure of feasibility and acceptability, which was administered at the end of every group session. The measure consists of five questions (each with three response options), which attempt to ascertain: (1) how much of the session was understood; (2) whether the group was helpful or not; (2) how helpful the specific exercises were; (4) how easy/hard were the exercises/practices to engage in; and (5) whether or not they enjoyed the session. The scale was presented in an easy-read format.

Self-Compassion Scale-Short Form (SCS Short-Form; Raes et al., 2011). This scale is a shortened 12-item version of the original 26-item Self-Compassion Scale (Neff, 2003b) designed to assess an individual's self-compassion across three components: self-kindness, common humanity, and mindfulness. This provides an overall self-

compassion score (Neff, 2015), or a two-factor structure where the original six subscales are separated into 'self-compassion' (positive subscales: self-kindness, common humanity, mindfulness) and 'self-criticism' (negative subscales: self-judgement, isolation, over-identification) factors (Costa et al., 2015; López et al., 2015). The original Self-Compassion Scale (SCS) has demonstrated good psychometric properties, with the SCS Short-Form demonstrating a near perfect correlation with the long form SCS ($r \geq 0.97$ all samples), and adequate internal consistency (Cronbach's alpha ≥ 0.86 in all samples). This measure has yet to be validated or adequately applied to research within an ID population. Permission was obtained from one of the original authors to adapt the scale for the identified population. Adaptations involved simplifying the wording of the questions so that these were more understandable and accessible for an ID population, as per consultation with specialists in the field of ID (i.e. an experienced clinical psychologist and Speech and Language Therapist).

The Psychological Therapy Outcome Scale for Intellectual Disabilities (PTOS-ID; Vlissides et al., in press). The PTOS-ID is a 29-item scale designed to measure both psychological distress (encompassing anger and anxiety) and positive wellbeing (psychological and interpersonal well-being) in people with ID, which lends itself favourably as a scale that is both accessible and meaningful to this population. Preliminary validation of the PTOS-ID suggests that it is a psychometrically robust measure of psychological distress

and well-being in this population, demonstrating good levels of construct and concurrent validity, reliability, and internal consistency (Vlissides et al., in press).

The adapted Social Comparison Scale (Dagnan & Sandhu, 1999). This scale, adapted for adults with ID from the original Social Comparison Scale (Allan & Gilbert, 1995), examines the way people evaluate themselves through comparisons with others, across the domains of rank and achievement, social attractiveness, and group belonging. Lower scores indicate feelings of inferiority and general low rank self-perceptions. The adapted scale has demonstrated a similar psychometric structure to the original scale (Dagnan & Sandhu, 1999), and reasonable Cronbach's alphas (ranging from $\alpha = 0.56$ to 0.76) for the full scale with this population (Dagnan & Sandhu, 1999; Paterson et al., 2012).

Statistical Analysis. Within-group comparisons for pre-group and post-group mean scores across outcome measures were performed. All data were tested for normal distribution.

Focus groups. A semi-structured interview schedule was utilised and adapted (with permission) from a previous study that developed the schedule to similarly investigate adult individuals' experience of attending CFT groups for acute inpatient settings (Heriot-Maitland et al., 2014). The focus groups were conducted at the end of the final

session so as to capture participants' immediate experiences of having undertaken and completed the group. Both focus groups were conducted by individuals who were not involved in the running of the group (a clinical psychologist and a trainee clinical psychologist), lasting for approximately 45 minutes. The focus groups were recorded via Dictaphone (with prior consent) in order to aid transcription. All six participants attended the focus groups.

Intervention

CFT is based on an evolutionary and neuroscience model of mind and emotional regulation, known as the 'Three Circles' model (Gilbert, 2009, 2014; Depue & Morrone-Strupinsky, 2005) depicted in Figure 1 (see Appendix 2), and suggests that some mental health difficulties arise when these affect regulation systems become unbalanced, particularly when the threat system becomes poorly regulated (Gilbert, 2010). CFT involves a significant amount of psychoeducation around the evolved nature of our minds that have left us with 'tricky brains', and how these three systems have become patterned, organised and conditioned by life experiences. A primary focus of CFT is to balance these systems through stimulating the affiliative/soothing system (Gilbert, 2010, 2014, 2015). This involves a series of compassion cultivation

exercises (CMT; Gilbert & Irons, 2005) such as attention training, soothing breathing rhythm, mindfulness, mentalizing, compassionate self-identity cultivation, the use of compassionate imagery, and enacting compassionate behaviours on a regular basis.

Figure 1. [INSERT HERE]

Adaptations to the group were made on the basis of recommendations for adapting psychological therapies and third-wave approaches for adults with ID (Taylor et al., 2013; Gore & Hastings, 2016), and clinical experience of working with ID populations. Adaptations included the presentation of psychoeducational material in a concrete, visual manner that minimised the use of abstract language (supported by the use of PowerPoint slides), and other visual methods to support understanding and demonstrate the purpose of particular practices/exercises. A supporting workbook that contained simple written and visual summaries of each session and accompanying practice(s) was also developed, to further aid understanding and support home/personal practice. Table 1 (see Appendix 1) summarises the content of each session.

Table 1. [INSERT HERE]

Each session lasted for approximately 90 minutes. Participants were instructed to practice the experiential exercises as part of personal practice between sessions, but frequency and duration of practice(s) was not recorded.

The groups were facilitated by the principal investigator (NEC), who has approximately three years supervised CFT practice, has attended numerous CFT trainings and workshops, and attends regular group supervision with Professor Paul Gilbert. Group 1 was co-facilitated by a senior clinical psychologist (JW) who has extensive experience adapting and delivering third-wave therapies for adults with ID. Group 2 was co-facilitated by a trainee clinical psychologist.

Results

Feasibility and acceptability data – attendance data and session-by-session feedback

Six out of the seven participants (86%) completed the intervention. One individual who completed the pre-group assessment process did not attend any of the sessions, and was thus not included in any further analysis. Four participants (66.66%) completed the full six sessions, with the remaining two participants (33.33%) completing five of the six sessions. Participant 1 missed Session 4 due to a misunderstanding around dates/times of the group for that session, and Participant 2 missed Session 1 due to difficulties in finding the location of the group. Due to its foundational and introductory nature, Participant 2 was given the Session 1 module in a one-to-one session facilitated by the principal investigator.

Table 2 (see Appendix 1) provides a summary of session-by-session feedback from the feasibility and acceptability measure, regarding perceived understanding and helpfulness of the group and practices. Participants clearly found the groups helpful and enjoyable, whilst there is more session-to-session variance in levels of understanding and perceived difficulty of experiential practices.

Table 2. [INSERT HERE]

Quantitative analysis

Data analysis. Although Kolmogorov-Smirnov tests were non-significant, these tests were considered underpowered due to the small sample size, preventing us from concluding that data met normality assumptions. Accordingly, Wilcoxon Signed-Rank tests were used to measure differences between pre-group and post-group scores across the measures, recommended as the most appropriate non-parametric test for a within-subjects repeated measures design for studies with small numbers of participants (Field, 2005). Table 3 (see Appendix 1) provides a summary of observed changes between pre-group and post-group mean scores across outcome measures.

Table 3. [INSERT HERE]

Self-compassion. Post-group total self-compassion scores were significantly higher than pre-group self-compassion scores (z = -1.99, p = 0.046). Using the two-factor structure, scores on the self-criticism factor significantly decreased pre to post-group (z = -2.21, p = 0.027), but there was no significant change on the self-compassion factor (z = -0.42, p = 0.674). Figure 2 (see Appendix 2) demonstrates changes in overall self-compassion for each individual participant.

Figure 2. [INSERT HERE]

Psychological distress and well-being. There was no significant change in overall psychological distress (z = -0.954, p = 0.34) or psychological well-being (z = -0.28, p = 0.783) scores. Figure 3 (see Appendix 2) demonstrates changes in overall psychological distress for each individual participant.

Figure 3. [INSERT HERE]

Social comparison. Post-group scores for social comparison (using the total score) were significantly higher compared to pre-group (z = -2.00, p = 0.046), indicating a reduction in unfavourable social comparisons and thus feelings of inferiority. Figure 4 (see Appendix 2) demonstrates changes in overall social comparisons for each individual participant.

Figure 4. [INSERT HERE]

Qualitative analysis

Data analysis. All data obtained from the focus groups was analysed utilising thematic analysis (Braun & Clarke, 2006). This analytical approach was chosen as its primary purpose is to capture emerging themes, which best fit the primary aims of this study in exploring feasibility and acceptability. Thematic analysis followed the six phases of analysis outlined by Braun and Clarke (2006), as described in Table 4 (see Appendix 1).

Table 4. [INSERT HERE]

Thematic analysis yielded four super-ordinate themes, with some containing sub-themes, which were consistently identified from the focus groups: (1) Motivation(s) for Attending; (2) Direct Experiences of the Group; (3) Overcoming Fears, Blocks, and Resistances to Compassion; and (4) Changes relating to Self, Other, and Experiences. All participants' names are pseudonyms.

Theme 1: "Wanting to feel better about myself" – Motivation(s) for attending

This super-ordinate theme describes participants' many motivations for attending the CFT group, and thus the beginning of their therapeutic journey. These motives were often *intrinsic* (i.e. from within), *extrinsic* (i.e. from others/the environment), or a combination of the two. Most participants' motives centred on the recognition of and desire to alleviate their own suffering.

Intrinsic. Three participants reported that their main motivation for attending the CFT group was to change the way that they felt about themselves:

> ...to make me feel better about myself. (Beatrice)
>
> Yeah, I think the same as well. (Kathy)

Having the motivation to care for oneself and one's well-being is seen as a crucial component of CFT, which leads to being able to engage with suffering and develop compassion. This is consistent with participants' reasons for joining the group. For one participant, this specifically seemed to be grounded in an awareness of the negative impact that shame and self-criticism had, and was having, on their lives:

> It's like, you've been, I've been beating myself up for such a long time, and even the last, forever...although I knew people felt the same way I did, anxious and scared and depressed and fed up, I always used to beat myself up to the point where I didn't want to be here anymore. (Kathy)

Half of the participants reported struggling to cope with specific events that had happened in their life, and that coming to the CFT group might help them (or give them the skills) to cope better with difficulties and suffering in life, as highlighted by Crispin:

> It's just like, like, I can't like see them [siblings] anymore, so I thought to come here to like help me out kinda cope sort of thing...with not seeing them. (Crispin)

Extrinsic. Some participants also acknowledged that other significant people in their life (e.g. family members, friends) had encouraged them to attend the CFT group, explaining to participants that it might benefit them in some way. Two of the participants differentially described how the advice of others may have been experienced as more caring and supportive (affiliative-focused), or tinged with criticism and potential rejection (threat-focused):

> My sister...said that there's a group starting...and it might help you because I've got issues, like...I've just recently lost Dad, so... (Anne)

and

> ...all my friends suggested that I should go to the group because they, they said they were getting a bit fed up of me being negative. (James)

James further describes how his many motivations to attend appeared to reflect a desire to suffer less, realising that his current ways of coping with life's difficulties were actually causing him great suffering, particularly in relation to his social relationships:

> I got to the stage where I got fed, fed up of lock, lock, locking me in my room, not socialising, wanting to be a calmer person, so so I went...I thought it's not help, helping

> locking myself in my room 'cos you wouldn't want a life at the end...it was getting to the stage where all my friends were getting upset... (James)

One participant, who had talked about numerous fears of attending the group, reported that encouragement from a peer had been a significant factor in feeling able to attend:

> Um, and when it was suggested to me again, uh had a word with my friend and she said "well you know, try it, you don't know what will happen until you try it." And to be honest I'm glad I did. (Kathy)

Theme 2: "It's like...you're not on your own" – Experiences of the group

Participants often described how their direct experiences of being in the group had been a positive experience and benefitted them in some way (subordinate theme of 'everything was helpful'). This super-ordinate theme highlights the process and content of the CFT group, how this helped to de-shame participants' suffering, and began to facilitate the cultivation of compassion (subordinate themes of 'we're not alone' and 'our brain works in mysterious ways').

Everything was helpful. A consistent narrative that emerged from all participants' responses was that they experienced the entirety of the CFT group as helpful:

> Um, everything about it. (Zooey)

> Yeah, everything really. (Crispin)

What emerged from participants' responses, and throughout the analysis, was that some of the participants appeared to find it difficult to articulate precisely *what* about the CFT group was most helpful:

> Ummm, everything really. Like, help me type of thing, stuff like that...like, how to like cope with things and stuff like that (Crispin)

These difficulties in being able to recall, describe and articulate specific aspects of their learning and experiences within the CFT group may be associated with participants having an ID. However, despite these difficulties, all participants were very clear in reporting that the CFT group had been personally (and collectively) beneficial to them in a meaningful way:

> I'm, I'm finding it really positive now thanks to this. (James)

> I think everything in, in its own way has helped us all in a different way. (Kathy)

The perceived benefits of attending and participating in the CFT group was further reflected in Crispin's response when talking about recommending the group to others, and why he would do so:

> Umm, it would probably help them through life or something...like, probably if they had a bad life, how to cope with their bad life. (Crispin)

We're not alone. Participants generally reported that the opportunity to share their stories and experiences of suffering within the CFT group was powerfully de-shaming. This process, aided by core CFT concepts/principles such as 'not your fault', appeared to begin to depersonalise suffering and reduce participants' sense of aloneness, as reflected by Kathy:

> It's like, you're not, you're not on your own. You know, there are other people that are going through the same thing...I'd say [chuckles], I've managed to realise that, that I'm not on my own. (Kathy)

These emotional shifts in turn appeared to be related to an increased sense of *common humanity*. The process of sharing and de-shaming participants' experiences and feelings helped them realise the normality of suffering as a shared human experience, and an increased sense of connectedness to/with others:

> Zooey: And being in like the same boat and all that

Crispin: Yeah

Interviewer: Ahhh, ok, so you learnt that everybody's in the same boat and

Crispin: Yeah

Zooey: Trying to get through life

Interviewer: Yeah?

Crispin: And we're not alone.

Our brain works in mysterious ways. One participant reported explicitly remembering some of the evolutionary concepts such as the 'tricky brain', but their articulation of this concept was vague and did not explicitly communicate a deeper level of understanding:

Zooey: The way our brain works and that

Interviewer: Ahhh okay, "the way our brain works." How do our brains work?

Zooey: In many mysterious ways!

This was also true for other core CFT concepts such as the 'Three Circles' affect regulation model. Participants demonstrated they had grasped some of the basic concepts, albeit displaying a degree of uncertainty when attempting to articulate their understanding:

Zooey: The red one is where you're worried a lot

Interviewer: Uh hum

Crispin: Hum

Zooey: The green one is where you're so peaceful and relaxed

Interviewer: Aahhhh

Zooey: and the blue one is...(hesitant pause)

Anne: In between

Zooey: Yeah, in between

Crispin: Yeah.

Furthermore, some participants appeared to demonstrate some level of deeper understanding about these concepts, but some of their responses continued to be vague. Such responses may be indicative of some of the theoretical/conceptual aspects of the intervention being a little too complex for participants to fully grasp:

Crispin: The green one's better

Zooey: Yeah

Interviewer: The green one's better. Brill. So is that where everybody is trying to get do you think?

Crispin: Yeah

Interviewer: Yeah? And then if somebody was in the red, how would they know?

Zooey: They'd be feeling stressed

Anne: They'd be down in the dumps

Zooey: Feeling stressed

Crispin: Yeah.

Theme 3: "Putting together the jigsaw" – Overcoming fears, blocks, and resistances to compassion

Many of the participants reported initially finding compassion exercises/practices strange and difficult:

> When I first did the breathing, I thought "what is he [therapist] on?!?"...you know, "this is daft!" (Kathy)

The same participant described how they felt their tendency to be self-critical made it difficult to be compassionate to themselves, and thus made it initially hard to engage in the compassion practices:

> I've always been the same: beatin' me self up, doin' it again, do it again...and the being kind to yourself doesn't happen. It's sort of...it's hard to be kind to yourself when you're always used to not being kind to yourself... (Kathy)

However, Kathy described how a sufficient level of trust in the therapist and safeness within the group allowed her to explore new things:

> But once I, once I let myself do it [the breathing], it was kind of relaxing, and it does help you out in ways you wouldn't even think about. (Kathy)

Kathy further describes how being able to take in compassion from others, and have it modelled first, was crucial in overcoming these fears, blocks, and resistances and being able to develop compassion for oneself:

> ...the being kinder part was nice because somebody else saw that in you, that you know is already there but you just can't access it...I think sometimes you just need to be shown a couple of times, and then it depends on how your head is. Maybe you can carry it through... (Kathy)

Another participant, who described having found it difficult their entire life to be compassionate to themselves, reported how they felt it was through repeated practice that they began to overcome these initial difficulties, and thus become more self-compassionate:

> Crispin: At first it was a bit hard, but the easier it got, but at first it's hard...
>
> Interviewer: Yeah?...do you feel like it's a bit easier to put it all into practice?
>
> Crispin: Yeah, like putting a jigsaw together and that! But with practice it gets easier.

Theme 4: "Looking at yourself from the inside" – Changes in relating to self, other, and experiences

This super-ordinate theme reflects how engaging in CFT-specific compassion practices within and outside (e.g. personal practice) the group appeared to result in significant *emotional* changes. The subordinate themes describe positive changes in participants' sense of self and self-to-self relating, and how compassion practice(s) appeared to be beginning to give them the strength to cope with difficulties and flourish in day-to-day life.

Finding the inner peace of you – feeling calmer. Participants unanimously reported significant positive emotional changes, particularly as a result of engaging in and practicing Calm Breathing (Soothing Breathing Rhythm). For many, this appeared to be reflected in increases in affiliative and contented emotion, such as feeling calmer, safer, and more relaxed, a core therapeutic target in CFT:

> I, I've learnt the breathing exercises can keep you, keep you more relaxed. (James)
>
> ...it, it sort of chills you out. (Kathy)
>
> Relaxing your body. (Crispin)

One participant described how the Calm Breathing exercise helped her find an inner point of safeness and stability:

> Interviewer: What would you say it's changed? What has it helped you do?
>
> Zooey: Be the...inner peace of you...like, looking at yourself from the inside.

Some participants described how engaging in these exercises helped regulate threat processing and threat-based emotions, such as worries and anxiety, whilst also increasing affiliative feelings of safeness, contentment, and well-being:

> Interviewer: Any other ways it has helped?
>
> Crispin: Urm (brief pause), trying to clear my mind [of my siblings] really, like, not seeing them again sort of thing...just like, be happy really and not worry about it. See like, 'cos I know they're safe kinda thing...

Coping with my inner self – increased self-compassion. Participants unanimously reported changes in self-to-self relating, but again their verbal accounts were often vague. A number of participants specifically reported that the group in general had contributed to a sense of increased self-understanding:

> It just...helped me understand myself a little bit better...urm, how to cope with my inner self, basically. (Anne)

For other participants, developing self-compassion through the compassion practices appeared to lead to increased self-acceptance, reduced shame and self-criticism, and positive changes in how they related to others and general experiences in life:

> ...I'm not that negative like I used to be...being kind, kinder to yourself ones help, 'cos 'cos I don't think much that I'm a weak link anymore... (James)

and

> ...and you know you can, you can find it in, in yourself to be nice to yourself, to be nice to other people...instead of being the one that...beating yourself up... (Kathy)

One participant reported how becoming more compassionate appeared to be a transformational process of becoming the version of themselves that they wanted to be, a key therapeutic process in CFT:

> Finding the person you really are...on the inside. (Zooey)

Having the courage – using practices in real life. The majority of participants were able to report and reflect on how they were attempting to generalise their learning and practices to everyday life, but again found it difficult to articulate *how* they were doing so and provide specific examples:

Interviewer: ...okay, so what sort of time of day do you tend to use it then?

Beatrice: Morning, noon and night! [laughs]

and

Interviewer: Are there any times when you've been having a tricky time but you were kinder to yourself?

Crispin: Probably every day, near enough!

One participant reported that they did not engage in personal compassion practice(s) outside of the group settings, who was unable to articulate specific reasons for this, despite reporting having benefitted from the practices within group sessions:

No, I don't do them at home. (Anne)

For a number of participants, it seemed that continuing to practice and apply compassion was beginning to have tangible impacts on their everyday functioning and well-being. Two participants described how undertaking compassion practices now helped them face and cope with stressful and emotionally overwhelming situations:

Crispin: ...before I, sometimes like when I go to places like the Day Centre and that, before I go upstairs sometimes

Interviewer: Ok, so when you go to places where you're worried?

> Crispin: Yeah...I do before I go there, and it makes me happier and that then.

and

> I close my eyes, and do the breathing exercises, and I find it helps me with me walk 'cos I used to have panic attacks when I went out, but it don't happen so much now. (Beatrice)

Another participant described how becoming more self-compassionate helped her recognise and validate her own emotions and needs, and develop the courage and confidence to be more assertive in her relationships, something she had previously felt ashamed of and feared doing:

> ...it felt, it felt like because I had the courage and the guts to say "hang on a minute", you know...I thought 'if you don't say it now, I'm never gonna do it, and it's gonna continue to get on my nerves, I'll beat myself up and I'll be back to square one', and I don't want that to happen again this time. (Kathy)

Kathy went on to describe how compassion practice was further beginning to transform her relationships with others:

> ...Dad...he used to hate talking to me 'cos I, I was like a spoilt three year old...he said it's a joy to speak to me now. He says it's almost like you've grown up overnight. (Kathy)

Discussion

This study of an adapted Compassion Focused Therapy group for adults with Intellectual Disabilities (CFT-ID) aimed to primarily explore and evaluate its feasibility and acceptability for this population. Results from the feasibility and acceptability measures, high rates of attendance, and qualitative data of participant's experience of the group, preliminarily suggests that CFT can be feasibly adapted for this population. Quantitative data obtained from pre and post-group measures tentatively suggest that adapted CFT may reduce self-criticism, shame and psychological distress, and improve levels of self-compassion in individuals with ID. These findings are consistent with outcomes in studies of group-based CFT in diverse adult clinical populations (Gilbert & Procter, 2006; Judge et al., 2012; Lucre & Corten, 2012; Heriot-Maitland et al., 2014). Due to the small sample size, and the associated lack of power inherent in the study, any findings regarding quantitative data are extremely preliminary and should be viewed with caution. Such data should be viewed in light of the fact that the main aim of this study was to determine the feasibility and acceptability of group CFT for this population, rather than establishing efficacy.

This is the first study to formally adapt and evaluate an explicitly compassion-focused group intervention for adults with ID. The mixed methods design provides promising

support for the notion that compassion can be taught and cultivated in adults with mild ID through the CFT model. Participants were able to report positive emotional changes and changes in self-to-self relating, as verified by verbal accounts of their experiences and those provided on self-report measures. These changes appeared to be related to processes and practices within the group. These changes occurred in a relatively short space of time (i.e. six weeks), with a clinical population who were highly self-critical and generally experiencing quite significant psychological distress. This tentatively suggests that group-based CFT may be a powerful intervention to reduce complex emotional and psychological difficulties in adults with mild ID.

Some of the data obtained from the acceptability and feasibility measures, supported by qualitative data from the thematic analysis, suggests that some of the CFT concepts may be too complex for individuals with ID to understand. For example, participants could recall some of the evolutionary concepts such as the 'tricky brain', but it was unclear whether they fully understood this and how they might helpfully apply it to themselves. It is possible that some of these concepts were presented in a manner that was still too abstract for participants to fully comprehend. Further work may be required to find more creative ways of presenting these concepts in a more concrete, and thus understandable, fashion. This may also be achieved by further reducing the content and spending more time on one particular concept per session, and extending

the number of sessions. Alternatively, complimentary one-to-one sessions may be a further means of tailoring and applying CFT concepts for individuals that support understanding and generalisation.

Nonetheless, all participants were able to engage with the various compassion practices in session and experience them as beneficial, even if at times encountering challenges when doing so. This was despite participants often finding it difficult to articulate their understanding of concepts and practices. For the vast majority of participants, they were able to start generalising the practices and learning to their day-to-day lives. This supports the notion that people with ID can make use of psychological principles and practices, without being able to describe them and/or changes in private events (Jones & Dowey, 2013). These processes have been observed in other studies examining the experiences of Dialectical Behaviour Therapy (DBT; Roscoe et al., 2015) and mindfulness groups (Yildiran & Holt, 2015) for adults with mild to moderate ID. CFT, like DBT and mindfulness, involves a high degree of experiential and behavioural teaching, practice(s) and learning. This may lend itself more favourably to this population, as it minimises the cognitive demands and verbal reasoning skills placed on participants that they might otherwise struggle with. The outcomes of this study provide further support for research suggesting that people with ID can benefit from psychological therapies as long as sufficient adaptations are

made (Lindsay et al., 2013), and in broadening the evidence-base for the use of third wave therapies with this population (Gore & Hastings, 2016).

One of the themes that emerged consistently from the qualitative analysis and group process was that most participants experienced initial difficulties in being able to generate compassion for themselves. These represent common fears, blocks, and resistances (FBRs) to developing compassion, which are increasingly reported in the non-ID adult literature (Pauley & McPherson, 2010; Gilbert et al., 2011; Lawrence & Lee, 2014). This is the first study to document the presence of FBRs to compassion in adults with ID, and that the process of overcoming these FBRs appears to be similar to those observed in non-ID adult populations (Lawrence & Lee, 2014). This was verified by participants' accounts of becoming increasingly self-compassionate through repeated practice and desensitisation to affiliative affect.

Limitations

There are a number of limitations in this study that require consideration. The sample size was very small, which reflected difficulties in being able to recruit larger numbers of participants, and the time-limited nature of the research project. This may be

attributable to geographical challenges specifically related to this study, as it was conducted in a relatively rural location. This can place severe restrictions on some individuals' ability to access services and groups, due to difficulties in securing and utilising appropriate transportation and support. Such recruitment difficulties maybe sufficiently ameliorated in a more urban setting, or where possible, processes are put in place to facilitate people's ability to attend groups. The sample was also not particularly heterogeneous, encompassing only individuals with a mild ID who were White British. This limits generalisability to other individuals with more significant IDs, or those from different ethnic/cultural backgrounds.

Given that this was a feasibility and acceptability study, no control group was utilised, nor were any longer-term outcome measures administered. Thus, it is not possible to begin to speculate about the medium to longer-term impacts of this intervention, whether or not any observed changes were due to specific group content or more general group processes, or its effectiveness compared with other adapted psychological interventions for this population. Future studies should consider expanding the number of sessions and group content whilst retaining a high degree of fidelity to the CFT model, before proceeding to pilot studies (Eldridge et al., 2016).

Other limitations relate to the fact that some of the measures, such as the SCS Short-Form (Raes et al., 2011), are not yet validated and/or standardised with ID populations. The modifications to the language used in the SCS-SF appeared to result in a tool that is understandable and accessible to individuals with mild ID. However, future studies should seek to psychometrically validate this measure with ID populations.

Conclusion

The findings from this study suggest that adapted CFT groups for adults with mild ID are feasible and acceptable, and that this maybe a promising method of intervention to ameliorate complex psychological difficulties in these individuals. Future studies utilising greater numbers of participants and further adaptations to the group structure and content are required, before conducting pilot studies in preparation for randomised controlled trials against other adapted group-based interventions for adults with ID.

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Appendix 1

Table 1. Summary content of the Growing Kind Minds CFT-ID group programme.

Session number and Title	Content and Key Elements	Specific Experiential Practice(s)
Session 1: Welcome! Introduction to Compassion	Introduction and exploration around the concept of compassion, how it might help/benefit, what might be difficult (fears/blocks/resistances)	Inner kind friendly voice
Session 2: Life is Hard – It's Not Your Fault	Introduction to 'tricky brain' and 'not your fault' concepts, importance of 'slowing down' (using breathing to calm body and mind)	Calm Breathing (Soothing Breathing Rhythm), Inner kind friendly voice
Session 3: Getting to know our brains and bodies better	Introduction to 'Three Circles' model and mini personalised formulation, 'multiple selves' concept	Three Circles, Calm Breathing, Compassionate Self
Session 4: Becoming our own Best Friend	Exploring differences between self-criticism and self-compassion, practice becoming the 'compassionate self' through acting, practice imagining compassion flowing from another	Calm breathing, Compassionate Self, Compassionate Image
Session 5: Being brave, letting go, and finding the good	Exploring how to put the 'compassionate self' to work (e.g. be brave, assertive, let go of and heal pain), exploring importance and effects of kindness and gratitude	Compassionate Self, Mindfulness with balloons, Gratitude and Savouring
Session 6: Keeping kindness going (review and maintenance)	Review concepts, practices and learning, explore how to help maintain practices in daily life, further brief compassion practices to incorporate into daily life	Compassion in the mirror, Hand on Heart meditation

Table 2. Session-by-session ratings of feasibility and acceptability (percentage of responses).

Question	Understanding?			Group Helpful?			Exercises Helpful?			Practice difficulty?			Enjoy group?		
	All	Some	None	Yes	No	D/K	Very	A bit	Not	Easy	A bit hard	Very hard	Yes	No	Not sure
Session 1 (*n* = 6)	50%	50%	0%	100 %	0%	0%	83.3 %	16.7 %	0%	66.6 %	16.7 %	16.7 %	100 %	0%	0%
Session 2 (*n* = 5)*	60%	40%	0%	100 %	0%	0%	100 %	0%	0%	100 %	0%	0%	100 %	0%	0%
Session 3 (*n* = 6)	83.3 %	16.7%	0%	100 %	0%	0%	100 %	0%	0%	50%	50%	0%	83.3 %	0%	16.7%
Session 4 (*n* = 5)**	80%	20%	0%	100 %	0%	0%	100 %	0%	0%	100 %	0%	0%	100 %	0%	0%
Session 5 (*n* = 6)	66.7 %	33.3%	0%	100 %	0%	0%	100 %	0%	0%	83.3 %	16.7 %	0%	100 %	0%	0%
Session 6 (*n* = 6)	66.7 %	33.3%	0%	100 %	0%	0%	66.7 %	33.3 %	0%	66.7 %	33.3 %	0%	100 %	0%	0%
OVERALL	**67. 7%**	**32.3%**	**0%**	**100 %**	**0%**	**0%**	**91.2 %**	**8.8 %**	**0%**	**76.5 %**	**20.6 %**	**2.9 %**	**97.1 %**	**0%**	**2.9%**

*Missing data from one participant due to unreturned feedback form.

**Missing data from one participant due to non-attendance.

Table 3. Descriptive and inferential statistics comparing changes in pre and post-group measures (*n* = 6).

Scale	Subscale	Pre-group mean (*SD*)	Post-group mean (*SD*)	*Z*-score	Associated *p* value
Self-Compassion Scale	Total Self-Compassion (mean total score)	1.99 (0.54)	2.81 (0.80)	-1.99	0.046*
	Positive sub-scale (self-compassion)	2.72 (1.08)	2.97 (0.90)	-0.42	0.674
	Negative sub-scale (self-criticism)	4.75 (0.29)	3.36 (0.92)	-2.21	0.027*
PTOS-ID	Psychological distress (total score)	28.00 (7.80)	25.67 (7.12)	-0.954	0.340
	Psychological well-being (total score)	25.00 (5.62)	24.67 (4.68)	-0.28	0.783
Social Comparison Scale	Total Social Comparison score	19.33 (4.68)	22.83 (4.17)	-2.00	0.046*

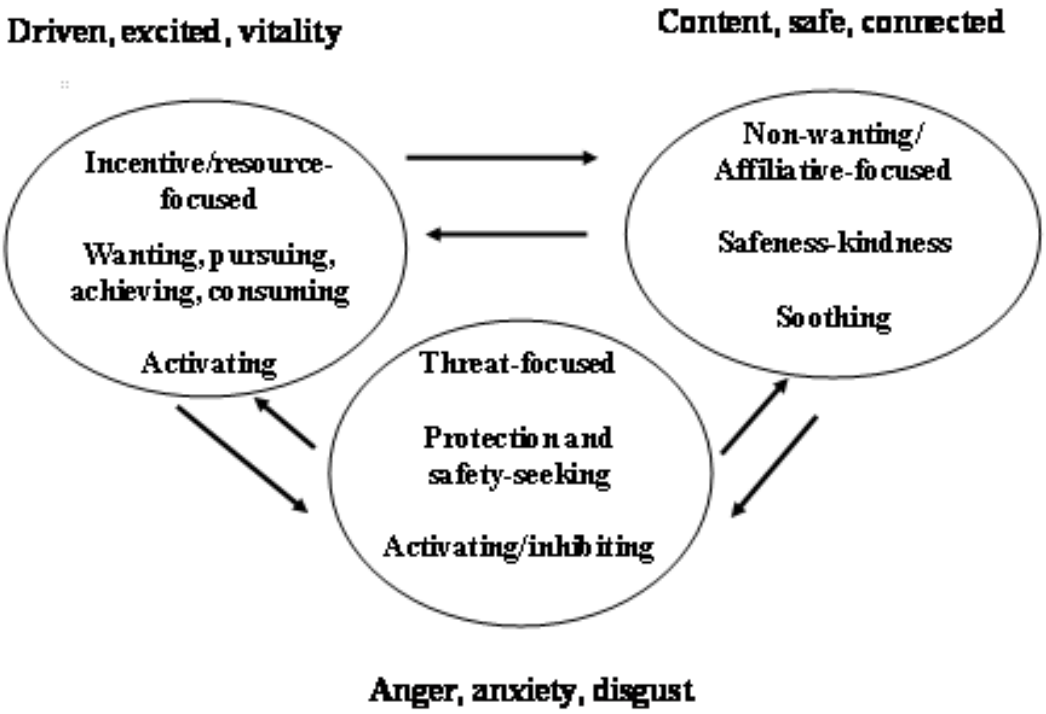
*significant at *p*=0.05 level (two-tailed test).

Table 4. Six steps of thematic analysis (adapted from Braun & Clarke, 2006).

Step 1: Familiarisation with the data	Focus group data fully transcribed (two separate transcripts), each read over several times before initially highlighting data relating to study aims.
Step 2: Generation of initial codes	Entire data set (i.e. across the two transcripts) were coded into groups that began to preliminarily identify repeated patterns in the data, collating all codes and related data extracts into a master coding table.
Step 3: Searching for themes	Collation and combining of different codes by looking for similarities, and grouping them together to come up with potential themes. This process was aided by developing thematic maps, which were also utilised to explore connections between possible themes.
Step 4: Reviewing themes	Meeting with an expert in qualitative analysis (GG), where analysis of data was shared and themes discussed, and to further visualise links and relationships between themes. This further involved ensuring that themes worked in relation to coded extracts and formed a coherent pattern, and that they also matched and reflected the entire data set, resulting in a final thematic map.
Step 5: Defining and naming themes	Clear definitions and names given to each theme (using quotes from participants as titles), accompanied by a detailed analysis to ensure that themes related to the overarching narrative within the data.
Step 6: Producing the report	Quotes and extracts were selected that clearly and vividly highlight themes, and support the overarching narrative and accompanying analysis.

Appendix 2

Figure 1. Three types of affect regulation system.



Source: From *The Compassionate Mind* (Gilbert, 2009), reproduced with permission from Constable & Robinson Ltd.

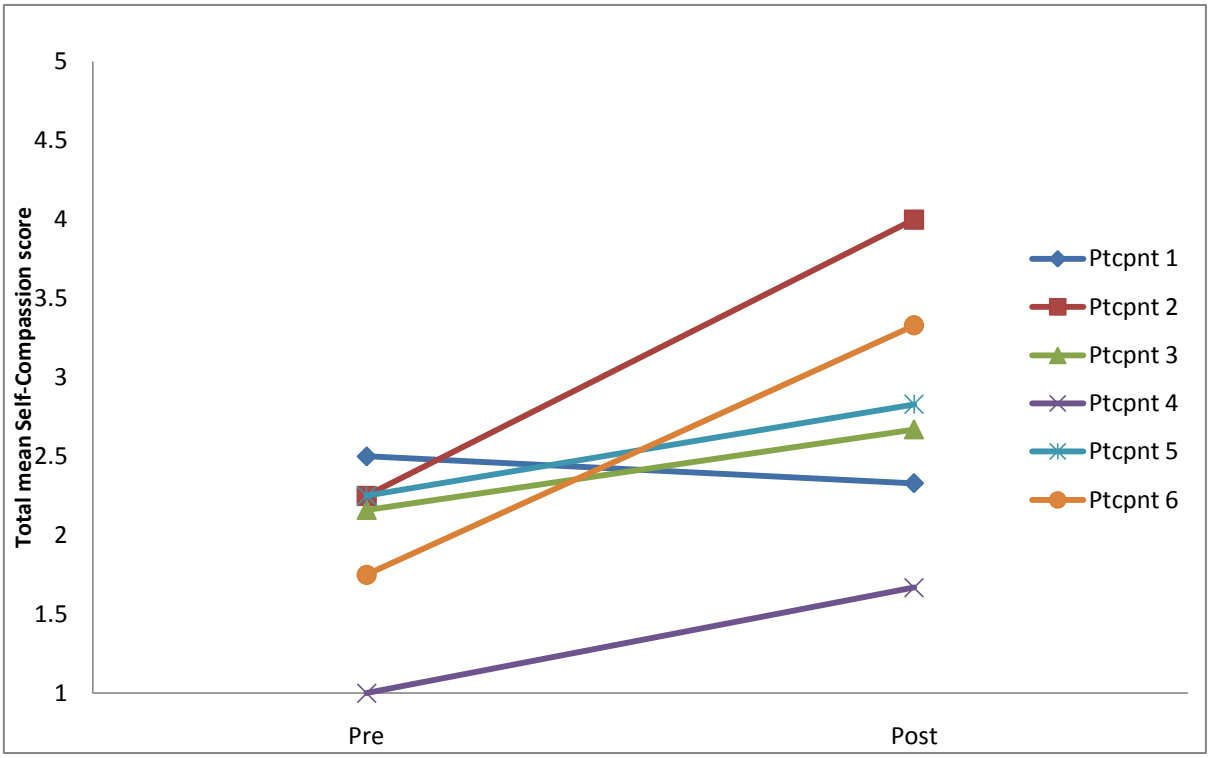


Figure 2. Changes in overall levels of self-compassion across participants pre to post-group.

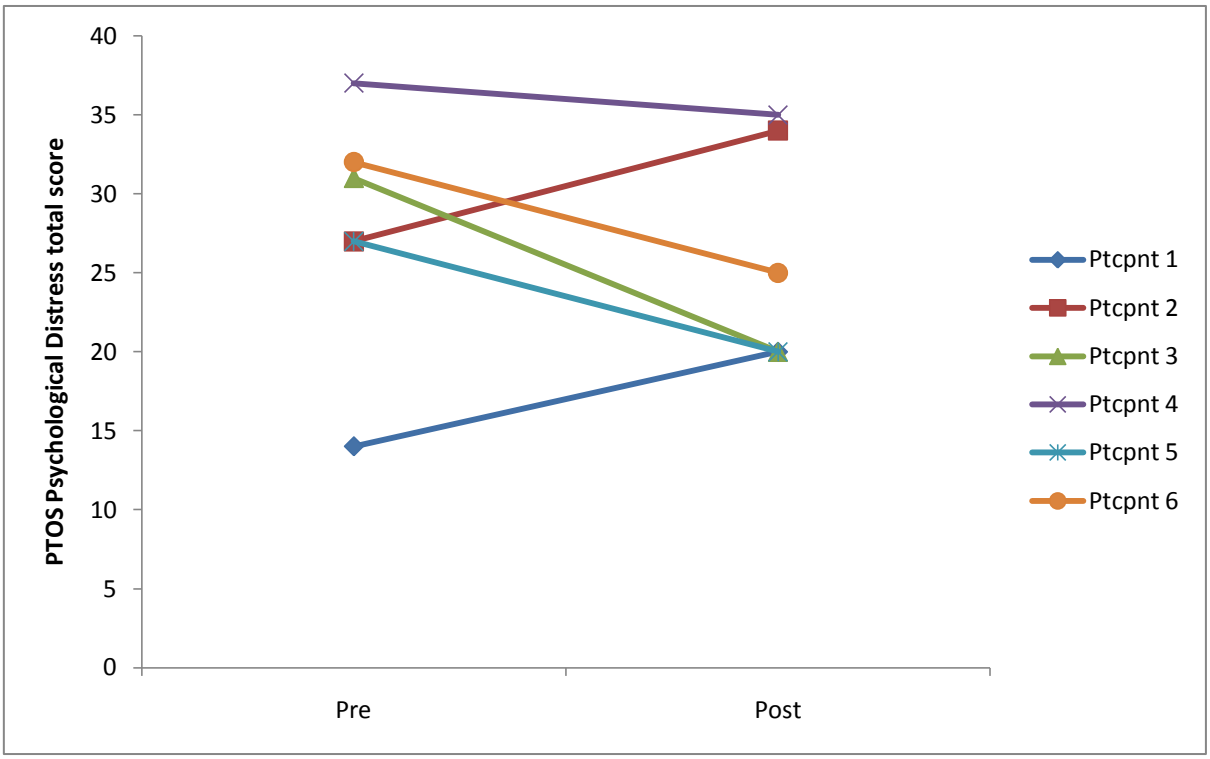


Figure 3. Changes in overall levels of psychological distress across participants pre to post-group.

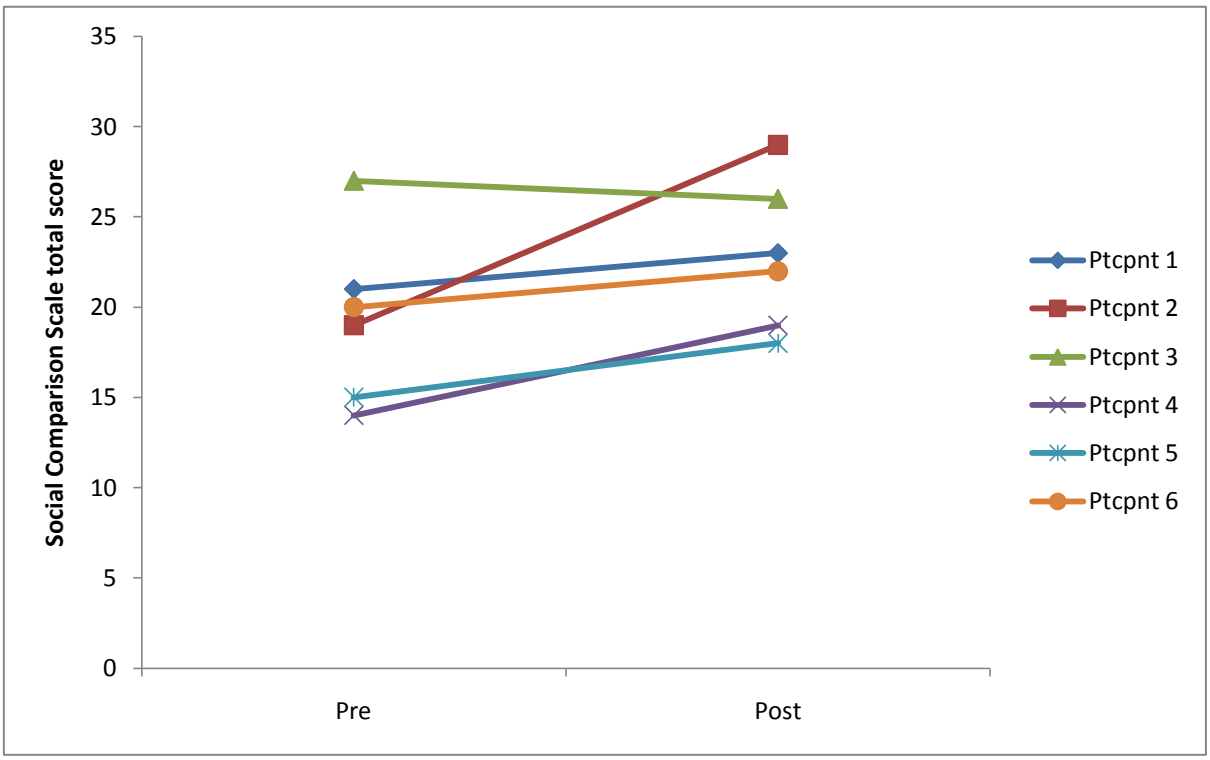


Figure 4. Changes in social comparisons across participants pre to post-group.

SECTION 4

Contributions to Theory and Clinical Practice

Summary of Findings

The literature review proposed that shame and shame-based processes may significantly contribute to the development and maintenance of psychological distress in adults with ID. The review highlighted that relatively little explicit attention has been given to the role of shame in ID research, and that there is a lack of adequate measures to properly assess shame in this population. The review also highlighted a relative lack of research, and availability, of adapted psychological interventions for adults with ID that explicitly address shame-based issues. Support for the premise of the literature review was confirmed in the empirical study, where participants reported high levels of self-criticism, relatively unfavourable social comparisons (i.e. high sense of inferiority), and relatively low levels of self-compassion.

The empirical study suggested that adapted Compassion Focused Therapy (CFT) is both a feasible and acceptable intervention in a group format for adults with ID. Support for the notion that self-compassion can be cultivated in adults with ID, through the specific practices of Compassionate Mind Training (CMT), was found through self-report and focus group data. However, some questions remained as to how fully participants understood specific CFT concepts, and how (or whether) this affected outcomes.

The findings of the literature review and empirical paper generated a number of implications for future research, theory development, and clinical practice.

Implications for future research and theory development

Theoretical issues around shame and self-compassion in adults with ID

Several theoretical issues in regards to the role of shame and shame-based processes in the development and maintenance of psychological distress in adults with ID require further investigation. It is not clear from the existing ID research which variables, such as frequency of shaming, who has done the shaming, or when shaming has occurred (e.g. period in life), have the most impact on the development of shame-based difficulties and subsequent psychological distress. Additionally, diverse biopsychosocial factors are proposed to be linked to the development of mental health difficulties in adults with ID (Irvine & Beail, 2016), such as exposure to life events, lower cognitive ability, and poorer living conditions (Cooper et al., 2007; Hulbert-Williams et al., 2014; Hatton et al., 2015). The relative contribution, overlap, and interaction of shame with these variables warrant further investigation.

There remains a theoretical question as to whether individuals with ID are more sensitive or prone to shame and shame-based process such as self-criticism and social comparison than non-ID populations. A number of studies included in the literature review indicated that this may well be the case (Esdale et al., 2015; Dagnan & Waring, 2004; Paterson et al., 2012; Garaigordobil & Pérez, 2007). Social rank theory (Gilbert, 1992, 1997) would suggest that perceived relative inferiority is associated with shame, social anxiety, the tendency to behave submissively, and thus depression (Gilbert, 2000a), to de-escalate attacks from others and prevent complete social rejection. Social rank and social mentality theory (Gilbert, 2005a) also suggest threat and social rank concerns guide self-other processing when one feels insecure and unsure about their abilities to create positive impressions in the mind of others, leading to a more

competitive orientation to social relationships (Leary, 1995; Gilbert, 1989, 2005b), resulting in becoming more prone to feeling inferior to others and vulnerable to psychopathology. As people with ID are potentially more likely to be placed in unwanted subordinate positions in their daily lives, this exponentially increases the opportunities for them to experience shame and for shame-based processes to be activated. Subsequently, it maybe that people with ID's sense of safeness in the world and self-worth is much more dependent on the views of others. One study in the literature review suggested that people with ID have an increased sensitivity to both criticism and praise, and thus maybe more prone to internalising others' views of them (Esdale et al., 2015).

Theoretically, it is also possible that cultural values such as seeing independence as the marker for social attractiveness, acceptance and approval are a crucial factor in engendering shame in adults with ID. This may lead to unhelpful social comparisons and the development of self-criticism when perceiving they have failed for not being able to do things independently. It would be interesting to investigate whether those individuals who value *interdependence* (Carnaby, 1998) over independence experience less or more shame, including the types of social comparisons they make. All of these theoretical issues warrant further investigation through novel research, which may include longitudinal, ethnographic, and qualitative methods.

It is also important to begin to investigate whether the processes underpinning the ability to be self-compassionate are the same or different for people with ID as compared to non-ID populations. Many individuals with ID may have experienced significantly disrupted attachments and care-receiving experiences (Pert et al., 2013), including infrequent and poor quality social support (McGillivray & McCabe, 2007).

Both social mentality and attachment theories of self-compassion have shown that warm, consistent care-giving from others and greater attachment security are essential to the optimal development of self-compassion in non-ID adults (Neff & McGehee, 2010; Pepping et al., 2015; Hermanto & Zuroff, 2016). Fear and lack of ability to be self-compassionate has also been linked to low recall of memories of parental emotional warmth in the general adult population (Kelly & Dupasquier, 2016), with early affiliative memories buffering the impact of shame experiences (Matos et al., 2015). Whether these theories fully apply to people with ID requires detailed further testing through research.

Investigating resilience and flourishing

In the empirical study, it was interesting to note that for one participant, as self-reported self-compassion increased from pre to post-group, so did their overall psychological distress score. This particular individual was enduring some significantly stressful life events relating to their living circumstances and interpersonal difficulties at the time. However, post-group this participant emphatically reported feeling much happier and content within themselves, but particularly feeling less frightened and ashamed of angry feelings they had previously avoided. Indeed, their angry feelings were an appropriate response to being in an environment they felt was overly-controlling, restrictive, and allowing them little autonomy.

Higher self-compassion is related to emotional and self-acceptance (Leary et al., 2007; Neff et al., 2007), thus functioning as a resilience mechanism and adaptive emotion regulation strategy (Trompetter et al., 2016). As such, corresponding elevated

psychological distress scores may (at times) represent individuals being more aware of, feeling less ashamed and avoidant of, and safer in (appropriately) expressing emotions such as anger. Indeed, compassion can often be about the journey into assertiveness (Gilbert & Choden, 2013; Kolts, 2012), in order to effectively self-advocate for one's needs and rights (Stuntzner & Hartley, 2015). Research may wish to disentangle these processes further, and in what circumstances this may apply. Furthermore, research could attempt to investigate whether helping individuals with ID become more self-compassionate increases their ability to self-advocate through a sense of empowerment (Stuntzner & Hartley, 2015).

Research may also wish to investigate the degree to which CFT helps people with ID *flourish* (i.e. live and function well), by buffering against psychopathology and promoting positive mental health (Muris & Petrocchi, 2015; Trompetter et al., 2016). This was in light of qualitative data provided from the empirical study, where some participants were able to identify significant positive changes in their daily functioning and interpersonal relationships as a result of attending the CFT group.

Development of shame and compassion measures

Whilst the literature review highlighted a number of existing stigma measures, these vary in terms of their reliability, and often inadvertently mix different aspects of shame (e.g. external and internal). These may differentially impact on psychological processes and may require slightly different interventions (Gilbert, 2010). Therefore, developing and validating appropriate measures of both external and internal shame for ID populations may be a fruitful avenue for future research.

The literature review and empirical paper highlighted that no compassion measures have currently been validated with ID populations. Research may seek to psychometrically validate the adapted version of the Self-Compassion Scale Short-Form (SCS-SF; Raes et al., 2011) used in the empirical study. The SCS-SF was chosen as the most researched, utilised, and validated measure of self-compassion in non-ID adult clinical populations (Castilho et al., 2015; Costa et al., 2015), even if there are on-going disagreements about its factor structure (Costa et al., 2015; López et al., 2015; Neff, 2015). Alternatively, other compassion measures, such as the Self-Other Four Immeasurables (SOFI; Kraus & Sears, 2008), could feasibly be adapted, trialled and psychometrically validated on ID adults. One of the potential appeals of the SOFI is that it places significantly less demand on language abilities. However, it has been significantly less utilised in research than the SCS-SF.

CFT delivered as an individual psychological therapy

The empirical study found that CFT is feasible, acceptable and potentially efficacious for adults with ID when delivered in a group format. However, evidence for CFT as an individually-delivered psychological therapy is virtually non-existent. Given that a protocol for adapting CFT for this population has now been developed, research should begin to investigate the feasibility, acceptability and preliminary efficacy of CFT for ID clients as a one-to-one therapy. This could initially be through detailed case studies/series and single-case designs, before proceeding to pilot, and (later) controlled trials.

Research into effects of specific CFT components

Although high levels of perceived understanding of sessions were reported, analysis of focus group data suggested that participants may have struggled to fully understand some of the CFT concepts. Future research may wish to separate out these components, such as the 'tricky brain' and 'three circles' concepts, more finely explore people with ID's understanding, and whether full understanding of these concepts impacts on outcomes.

Previous research has suggested that some individuals with ID may struggle with aspects of mental imagery (Brown & Bullitis, 2006). Focus group data from the empirical study indicated that participants could experience, be aware of, and engage in mental imagery. This is further supported by research that suggests people with ID may have relatively good imagery capacities (Roskos-Ewoldsen et al., 2006). Participants were also able to notice and comment upon the emotional/neurophysiological effects of imagery. This may have been because very early on in the group, a concrete exercise to explain and experientially learn the nature and power of imagery was undertaken. This is an essential and core process to the CFT model, in explaining how external and internal stimuli stimulate the same neurophysiological/processing systems in our brains (Gilbert, 2010). Thus, it may not be the case that individuals with ID don't experience mental imagery, but that they are often not aware of it or cannot *describe* it (Brown & Bullitis, 2006). Future research may wish to further investigate the imagery-related components and practices, in order to fully explore these processes and issues further.

Researching practice-related variables and effects

The empirical study did not explicitly measure factors such as frequency and duration of engagement in home practice, which may well have had a significant impact on outcomes. Indeed, one participant in the empirical study explicitly stated that they did not engage in any home practice. Research into the effects of long-term practice of mindfulness in individuals with ID has suggested that practice-related variables may significantly affect outcomes (Hwang & Kearney, 2013). Future research should therefore seek to more systematically investigate and measure home practice-related variables, and measure effects on subsequent outcomes.

Carer/supporter participation

Lack of space in the empirical paper precluded the exploration and analysis of carer/supporters' observations of change in participants' behaviour. However, analysis of focus group data highlighted a number of responses where carers/supporters voiced noticing positive changes in the individuals they were supporting. These tended to be emotional (e.g. increased calmness, more relaxed) and relational (e.g. more open, kinder). Future studies may wish to take appropriate proxy measures or interviews with carers/supporters to further verify noticeable behavioural change.

On a related note, future research may wish to formally consider the involvement and utilisation of carers/supporters. Research may wish to investigate whether the involvement of others close to participants has a significant impact on the following: (a) participation in the group (whether their presence facilitates or inhibits group processes); (b) learning of skills and generalisation to everyday life; and (c) outcomes.

Other adapted group programmes for ID that involve carer/supporter participation report that such participation appears to greatly influence participants' motivation to attend therapy and engage in home practice (Idusohan-Moizer et al., 2015), and better outcomes (Rose et al., 2005). This was not directly accounted for in the empirical study, and requires further investigation.

Implications for clinical practice

Referrals and recruitment

Reflections on the recruitment process of the empirical study highlighted potential issues around referrals. It was clear that the language of shame is rarely used or fully understood by fellow mental health professionals in ID services. This is supported by sociological research which suggests that shame remains taboo in society, research, and clinical domains (Scheff, 2016). If considering running CFT as an individual or group therapy, clinicians should be mindful of the need to provide sufficient education and information around shame and shame-based difficulties to referring parties, to ensure appropriate referrals are made. This is likely most feasibly achieved through presenting and disseminating such information at departmental meetings (e.g. referral/allocation meetings), as per the empirical study.

Access to transportation

'Structural' aspects of groups, such as picking an accessible location and providing transport for those who need it, have been identified as contributors to the positive

functioning of group interventions (Heneage & Neilson, 2012). A clear constraining factor in the recruitment process for the empirical study appeared to be geographical and practical restrictions related to the rural location of the study. Whilst this did not appear to be a factor for participants who attended, potential appropriate referrals may not have been made due to difficulties in securing additional support and transportation. These may not be significant issues (or evaporate) in services based in more urban settings.

Nonetheless, it is important for clinicians to consider these contextual and environmental factors when setting up groups, particularly in more rural locations. If doing so, it may require clinicians to creatively advocate for services such as funded/subsidised transportation and support for individuals with ID to attend groups. Transport disadvantage and lack of carer/friend support is often cited by people with ID as a significant barrier to social inclusion and participation (Abbott & McConkey, 2006; Beart et al., 2001). Psychological models have been proposed and evidenced as to how transport and mobility can either facilitate or inhibit well-being (Delbosc, 2012). This research often highlights that transport disadvantage is linked to social exclusion and lower psychological/emotional well-being (Delbosc & Currie, 2011; Vella-Brodrick & Stanley, 2013). Accordingly, an inability to support individuals with ID to attend groups may compound the shame and related social exclusion, isolation and disconnection many of these individuals experience.

Clinical psychologists are in a unique position to potentially profoundly influence the development and provision of the services they work in. Utilising transport disadvantage research to highlight the *emotional* (rather than purely economic) costs of not facilitating access to appropriate transportation may be an important first step

in increasing access to psychosocial interventions for adults with ID. There are existing community transportation programs that have been successfully trialled and implemented in other countries (Battelino, 2009). The rationale for doing so could further be enhanced by demonstrating the longer-term cost-effectiveness to ID services of running groups. Cost-effectiveness thus remains a further research question to be investigated, and for clinicians to potentially demonstrate through service evaluation(s).

Offering CFT as part of a stepped-care model

As shame and self-criticism are transdiagnostic issues, this widens the scope for potentially suitable referrals. The empirical study demonstrated that CFT was feasible and acceptable to individuals with ID with comorbid mental health issues, which potentially renders it a cost-effective way to deliver a powerful psychological intervention to as many people as possible. CFT could thus feasibly be integrated into a stepped-care intervention model in ID services (Jackson & Beail, 2016), where clinicians could increase accessibility by offering CFT as a group and individual therapy. Given its potential as a therapy to address transdiagnostic issues and processes, CFT may be a particularly effective and cost-efficient intervention for clinicians to establish in ID services. This could include integrating CFT principles and practices into other compatible transdiagnostic therapy programmes that are beginning to show promise for adults with ID (Lindsay et al., 2015).

A number of participants in the empirical study also reported worrying about the group ending, particularly that they would not be able to apply what they had learned

and maintain the gains they had made. Clinicians may be able to address these issues by establishing top-up or booster sessions, in order to consolidate skills and emotional benefits (Wellman et al., 2015).

Assessing, formulating, and treating shame in therapy

The literature review highlighted that shame and shame-based processes may play a significant role in the development and maintenance of psychological distress in people with ID. Clinicians may wish to use the Perceived Stigma of Intellectual Disability scale (PSID; Ali et al., 2008), adapted Social Comparison Scale (Dagnan & Sandhu, 1999), and the self-criticism factor of the adapted Self-Compassion Scale Short-Form (Raes et al., 2011) as indicators of external and internal shame in adults with ID. Additionally, clinicians can be sensitive to how people with ID interact with them, and the language they use to describe themselves. Indicators of shame may be calling themselves 'bad, silly, stupid', having a sense that they are 'different' and feel something is 'wrong' with them, and feeling as if they are alone or 'the only one'. Behavioural indicators may include averted eye gaze, attempts to hide/conceal (e.g. thoughts, feelings, behaviours) when discussing emotionally salient topics, inhibition and lack of confidence, and excessive acquiescence (Gilbert, 2000[b]; Keltner & Harker, 1998).

When working with individuals with ID who have shame-based issues, clinicians need to be mindful of the language they use in describing and making sense of their difficulties. CFT emphasises the functional nature of people's difficulties, seeing these as safety strategies that have developed to keep them safe from perceived (and real)

threats. This circumvents the language of maladaptive and distorted thinking used within some Cognitive Behavioural Therapies, which may serve to maintain some people's sense of shame (Gilbert, 2010).

It is important for clinicians to be mindful of the fact that people with ID face frequent experiences of external shame (i.e. stigmatisation) and perceived failure in their daily lives. Thus, their social rejection and exclusion is *real,* and their emotional and behavioural responses are understandable ways of attempting to cope with these fears. Equally, the social comparisons they make are likely reflective of the social environments they find themselves in (MacMahon & Jahoda, 2008). This calls for clinicians to make thorough formulations that properly take into account the environmental and interpersonal contexts in which people with ID currently operate in (Dagnan, 2007; Jahoda et al., 2009)

Commensurate with other therapeutic approaches, helping people with ID deal with the emotional experiences (Hebblethwaite et al., 2011) and beliefs that stem from these real life challenges maybe an important process in reducing shame, rather than challenging 'maladaptive' thinking (Jahoda, 2016).

Further adaptations and supporting materials

All of the participants in the second group of the empirical study requested CDs of the compassion practices to listen to at home. Further exploration revealed that for these participants, it was the warm, calm, soothing tone of the therapist's voice that stimulated compassionate feelings and enabled them to really benefit from the practices. Personalised CDs were subsequently recorded and given to these

participants at the end of treatment, after the post-session assessment was completed.

When conducting CFT with ID clients, it may be especially important for clinicians to provide, adapt and tailor resources that support home/personal practice, that more easily allow them to 'access' their Compassionate Mind. This is supported by research examining the use of similar strategies in supporting adults with ID to continue using mindfulness practices after attending introductory workshops (Chapman & Mitchell, 2013). Equally, it may be important to utilise more sensory-based compassion exercises, such as compassionate touch or smells, for clients with more significant ID.

Working with fears, blocks, and resistances (FBRs) to compassion

The empirical study highlighted that for the majority of participants, attempting to initially practice and cultivate self-compassion was difficult. Some participants described how this initially felt hard, strange, weird, and a little frightening. As highlighted in the empirical paper, these represent common fears, blocks and resistances (FBRs) to compassion that are increasingly recognised and documented in the non-ID adult literature (Gilbert et al., 2011; Lawrence & Lee, 2014).

If clinicians are attempting to help ID clients become more compassionate to themselves (and others), it is important to be mindful that these FBRs are likely to arise, and to normalise and validate these reactions. Working through these FBRs appears to be similar to the process of doing so in mainstream adult clinical populations (Lawrence & Lee, 2014). Therefore, clinicians should not be discouraged when faced with these issues, and should proceed with gradually exposing and

desensitising ID clients to affiliative affect as proposed in a CFT framework (Gilbert, 2010). Indeed, the empirical study highlighted how proceeding in this manner helped many participants slowly begin to let go of such fears and self-criticism, and become more used to (and emotionally reassured by) being compassionate towards themselves.

In further assisting clients with ID to cultivate compassion in therapy, the empirical study highlighted the centrality of therapeutic relationships in fostering the ability to be self-compassionate. Indeed, a number of participants spoke about how experiencing compassion from and having it modelled first by others was central to the process of developing self-compassion. This is supported by growing research in non-ID adult populations (Hermanto & Zuroff, 2016), in that helping self-critical individuals overcome fears of receiving compassion, and experiencing and internalising compassion from the therapist, buffers against depression (Hermanto et al., 2016). Therapy process research in adults with borderline to mild ID further supports this notion, where individuals highlight that it is warm, empathic and validating (therapeutic) relationships that are particularly important to and valued by them, potentially enhancing self-acceptance and feelings of social safeness (Pert et al., 2013).

Fostering appropriate emotional support and supporting families

Following on from the above, clinical psychologists could help to ameliorate shame and foster compassion at the systemic level by working with carers/supporters and teams. Indirect work may seek to influence the *quality* and *style* of support received by people with ID (Pert et al., 2013). This could be achieved through the facilitation of

workshops for both carers and teams, utilising a CFT approach and formal Compassionate Mind Training (CMT; Gilbert & Irons, 2005). Workshops could focus on cultivating both self *and* other-focused compassion for carers/supporters, to most skilfully regulate their own and others emotions. Modern acceptance and mindfulness oriented behavioural interventions for caregivers of adults with ID have demonstrated promising benefits and outcomes for both parties (Singh et al., 2016; Noone & Hastings, 2009, 2010; Bethay et al., 2013; McConachie et al., 2014). This might also prove to be a more viable method of intervention with individuals who have more significant ID (Reid et al., 2015).

Clinicians may also need to be mindful of the need to support and work with families of individuals with ID. Many experience reflected shame, otherwise known as courtesy stigma (Ali et al., 2012), which is stigma by association. Furthermore, family members/caregivers can also internalise shame, from experiences of being shamed by members of the public for having a 'disabled' family member, otherwise known as affiliate stigma (Ali et al., 2012; Werner & Shulman, 2013, 2015). Helping family members feel emotionally connected and supported, including involving them in CFT groups, may be compassionate ways of ameliorating this type of shame and improving family/caregivers' emotional well-being (Cantwell et al., 2015).

Public and community interventions to address shame

The literature review, and the existing literature on stigma related to ID, highlights the continued role of external and internal shame in both psychological distress and health inequalities in individuals with ID (Ali et al., 2012, 2015; Emerson et al., 2010). This

coincides with recent calls for global action to challenge intellectual disability stigma, as people with ID remain one of the most marginalised groups in society across countries (Scior et al., 2015, 2016). Shame is eminently about the experience of social rejection and exclusion, and so fits with long-standing agendas around promoting social inclusion for people with ID. Rather than solely working with individuals, it is also important for psychologists to attempt to positively influence the wider social contextual conditions in which people with ID live.

Drawing on the field of stigma research, several forms of public health intervention may be fruitful avenues for psychologists to further help reduce shaming experiences and increase compassion for people with ID. These include public health interventions such as educational and national initiatives that attempt to raise awareness and understanding of ID (Scior et al., 2015), and those that directly attempt to address people's implicit and explicit attitudes towards people with ID (Wilson & Scior, 2015). Recent stigma research suggests educational programs need to be contact-based, so that people's fears and anxieties around interacting with people with ID are ameliorated through processes of lowering social distance, increasing familiarity, and acceptance through feeling calmer (i.e. socially safer) as a result of such contact (Werner, 2015). *Quality* of contact, in creating opportunities for affiliative and co-operative interactions, is crucial for increasing social acceptance and thus reducing shame (Keith et al., 2015). This could also be achieved by psychologists and people with ID engaging in co-production (Roberts et al., 2012), both within services and in community-based interventions, which are already beginning to demonstrate promise (Seewooruttun & Scior, 2014). Alternatively, working with ID individuals to set up community support groups that increase their sense of *connectedness* (Cummins &

Lau, 2003; Dozorenko et al., 2015) may be a fruitful avenue for reducing their sense of shame and the isolation that typically ensues.

Personal Reflections

The process of attending the NHS Research Ethics Committee (REC) was both a frustrating and excellent learning experience. I was aware that my frustration arose initially from the REC's insistence on specifically presenting a protocol to the panel as to how undue distress and disclosures maybe managed. This frustration related to some of the committee members' seeming lack of understanding that this was part of routine clinical practice, and had already been outlined in the ethics form. Some of my initial thoughts and reactions were that the committee might be being overly-cautious because of the nature of the population in question. Indeed, it has been suggested that attitudes of ethics committee members can lead to the exclusion of valid and valuable research opportunities involving individuals with ID (Lai et al., 2006).

However, further reflection on this issue allowed me to realise that the job of the REC is primarily to ensure the safety and well-being of this potentially vulnerable population, and ensuring ethically strong research is conducted (McDonald et al., 2009; McDonald & Kidney, 2012). This was ultimately a helpful process in encouraging me to ensure that there was a clear, systematic protocol in place before the research commenced, that guaranteed the safeguarding of my participants should these issues have arisen.

The REC also helped to bring awareness to areas of the research project that might need further refinement and/or development, such as the feasibility and acceptability

measure that was subsequently developed. The information obtained from this measure has been a crucial part of the analysis. Contemplating on these experiences, I am left with a feeling of gratitude for what I now perceive to be their wise, helpful and supportive advice. This also demonstrated to me how the process of planning and applying for ethical approval can sometimes leave one 'not being able to see the wood for the trees'!

There were times when I experienced doubts about my ability to complete the research as initially planned, particularly when only being able to recruit three participants for the first round of the group. These doubts were contained by mindfully sitting with the uncertainty, and having faith that the recruitment phase had started early enough to recruit more participants for another round of the group. Having an experienced and supportive supervisor who had been through this process, coupled with their expressed confidence and total belief in the project, was both reassuring and motivating. This further raised awareness of the potential challenges in attempting to set up (and recruit for) groups in daily clinical practice. This included time-intensive but necessary visits to potential referral teams, and the realisation that referrals sometimes only start to increase once a group has become more established within a service.

The whole research process was both challenging and incredibly rewarding. Conducting a mixed methods study, whilst also having to formally adapt a psychological therapy, felt at times to be overly-ambitious. The process of researching adaptations and creating resources was incredibly time-consuming, and an intellectual challenge in retaining as high a degree of fidelity as possible to the CFT model. Formal qualitative analysis was not something that I was particularly confident or fluent in, but

one that I wanted to pursue. The main motivation for committing to this methodology was to develop and provide an evidence-based psychological intervention for a marginalised population that often have limited access to such interventions, and are often excluded from research. I felt this was an important opportunity for adults with ID not only to experience a potentially helpful psychological therapy, but also to share their experiences that may shape future research and provision of helpful psychological interventions. Seeing and hearing participants' clearly benefitting from participating in and contributing to the group has ultimately shown that committing to this methodology was more than worth the effort.

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ETHICS APPENDIX

Bangor University Ethics

Application for Ethical Approval

Project Title: Growing Kind Minds: A feasibility study and preliminary trial of adapted group-based Compassion Focused Therapy for people with Intellectual Disabilities (CFT-ID)

Principal investigator: Clapton, Neil

Other researchers: Williams,Jonathan, Jones,Robert

Pre-screen Questions

Type of Project
D.Clin.Psy

What is the broad area of research
Clinical/Health

Funding body
Internally Funded

Type of application (check all that apply)
Study in the area of health and social care requiring sponsorship from BU. Project requiring scrutiny from an outside body which has its own ethical forms and review procedures

Proposed methodology (check all that apply)
Questionnaires and Interviews. Other type of research, please specify
Further details: Adaptation of group intervention, pilot and feasibility study

Do you plan to include any of the following groups in your study?

Does your project require use of any of the following facilities and, if so, has the protocol been reviewed by the appropriate expert/safety panel? If yes please complete Part 2:B

If your research requires any of the following facilities MRI, TMS/ tCS, Neurology Panel, has the protocol been reviewed by the appropriate expert/safety panel?
Not applicable (the research does not require special safety panel approval)

Connection to Psychology, (i.e. why Psychology should sponsor the question)
Investigator is a student in Psychology (including the North Wales Clinical Psychology Programme). Investigator is collaborating with staff member or student in psychology and is a named researcher on the project (including the North Wales Clinical Psychology Programme)

Does the research involve NHS patients? (NB: If you are conducting research that requires NHS ethics approval make sure to consult the Psychology Guidelines as you may not need to complete all sections of the Psychology online application)
Yes, NHS IRAS application attached.

Has this proposal been reviewed by another Bangor University Ethics committee?
No

NHS checklist. Does your study involve any of the following?
Use of NHS Staff or resources e.g. recruitment through the NHS, access to Medical records, use of premises etc.. Involve research participants identified from or because of their past or present use of NHS services. Including participants recruited through these services as healthy controls?

Part 1: Ethical Considerations

Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?
Yes

Will you tell participants that their participation is voluntary?
Yes

Will you obtain written consent for participation?
Yes

If the research is observational, will you ask participants for their consent to being observed?
N/A

Will you tell participants that they may withdraw from the research at any time and for any reason?
Yes

With questionnaires, will you give participants the option of omitting questions they do not want to answer?
Yes

Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?
Yes

Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?
Yes

Will your project involve deliberately misleading participants in any way?
No

Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort? If "Yes", give details and state what you will tell them to do should they experience any problems (e.g., who they can contact for help)
Yes

Is there any realistic risk of any participants experiencing discomfort or risk to health, subsequent illness or injury that might require medical or psychological treatment as a result of the procedures?
No

Does your project involve work with animals? If "Yes" please complete Part 2: B
No

Does your project involve payment to participants that differs from the normal rates? Is there significant concern that the level of payment you offer for this study will unduly influence participants to agree to procedures they may otherwise find unacceptable? If "Yes" please complete Part 2: B and explain in point 5 of the full protocol
No

If your study involves children under 18 years of age have you made adequate provision for child protection issues in your protocol?
N/A

If your study involves people with learning difficulties have you made adequate provision to manage distress?
Yes

If your study involves participants covered by the Mental Capacity Act (i.e. adults over 16 years of age who lack the mental capacity to make specific decisions for themselves) do you have appropriate consent procedures in place? NB Some research involving participants who lack capacity will require review by an NHS REC. If you are unsure about whether this applies to your study, please contact the Ethics Administrator in the first instance
N/A

If your study involves patients have you made adequate provision to manage distress?
Yes

Does your study involve people in custody?
No

If your study involves participants recruited from one of the Neurology Patient Panels or the Psychiatry Patient Panel then has the protocol been reviewed by the appropriate expert/safety panel?
N/A

If your study includes physically vulnerable adults have you ensured that there will be a person trained in CPR and seizure management at hand at all times during testing?
N/A

Is there significant potential risk to investigator(s) of allegations being made against the investigator(s). (e.g., through work with vulnerable populations or context of research)?
No

Is there significant potential risk to the institution in any way? (e.g., controversiality or potential for misuse of research findings.)
No

Part 3: Risk Assessment

Is there significant potential risk to participants of adverse effects?
No

Is there significant potential risk to participants of distress?
No

Is there significant potential risk to participants for persisting or subsequent illness or injury that might require medical or psychological treatment?
No

Is there significant potential risk to investigator(s) of violence or other harm to the investigator(s) (e.g., through work with particular populations or through context of research)?
No

Is there significant potential risk to other members of staff or students at the institution? (e.g., reception or other staff required to deal with violent or vulnerable populations.)
No

Does the research involve the investigator(s) working under any of the following conditions: alone; away from the School; after-hours; or on weekends?
No

Does the experimental procedure involve touching participants?
No

Does the research involve disabled participants or children visiting the School?
No

Declaration

Declaration of ethical compliance: This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research. I confirm that I am aware of the requirements of the Data Protection Act and the University's Data Protection Policy, and that this research will comply with them.
Yes

Declaration of risk assessment The potential risks to the investigator(s) for this research project have been fully reviewed and discussed. As an investigator, I understand that I am responsible for managing my safety and that of participants throughout this research. I will immediately report any adverse events that occur as a consequence of this research.
Yes

Declaration of conflict of interest: To my knowledge, there is no conflict of interest on my part in carrying out this research.
Yes

Part 2: A

The potential value of addressing this issue

Hypotheses

Participants recruitment. Please attach consent and debrief forms with supporitng documents

Research methodology

Estimated start date and duration of the study.

For studies recruiting via SONA or advertising for participants in any way please provide a summary of how participants will be informed about the study in the advertisement. N.B. This should be a brief factual description of the study and what participants will be required to do.

Part 2: B

Brief background to the study

The hypotheses

Participants: recruitment methods, age, gender, exclusion/inclusion criteria

Research design

Procedures employed

Measures employed

Qualifications of the investigators to use the measures (Where working with children or vulnerable adults, please include information on investigators' CRB disclosures here.)

Venue for investigation

Estimated start date and duration of the study (N.B. If you know that the research is likely to continue for more than three years, please indicate this here).

Data analysis

Potential offence/distress to participants

Procedures to ensure confidentiality and data protection

**How consent is to be obtained (see BPS Guidelines and ensure consent forms are expressed bilingually where appropriate. The University has its own Welsh translations facilities on extension 2036)*

Information for participants (provide actual consent forms and information sheets) including if appropriate, the summary of the study that will appear on SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.

Approval of relevant professionals (e.g., GPs, Consultants, Teachers, parents etc.)

Payment to: participants, investigators, departments/institutions

Equipment required and its availability

If students will be engaged a project involving children, vulnerable adults, one of the neurology patient panels or the psychiatric patient panel, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)

If students will be engaged in a project involving use of MRI or TMS, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)

What arrangements are you making to give feedback to participants? The responsibility is yours to provide it, not participants' to request it.

Finally, check your proposal conforms to BPS Guidelines on Ethical Standards in research and sign the declaration. If you have any doubts about this, please outline them.

Part 4: Research Insurance

Is the research to be conducted in the UK?
Yes

Is the research based solely upon the following methodologies? Psychological activity, Questionnaires, Measurements of physiological processes, Venepuncture, Collections of body secretions by non-invasive methods, The administration by mouth of foods or nutrients or variation of diet other than the administration of drugs or other food supplements
Yes

Research that is based solely upon certain typical methods or paradigms is less problematic from an insurance and risk perspective. Is your research based solely upon one or more of these methodologies? Standard behavioural methods such as questionnaires or interviews, computer-based reaction time measures, standardised tests, eye-tracking, picture-pointing, etc; Measurements of physiological processes such as EEG, MEG, MRI, EMG, heart-rate, GSR (not TMS or tCS as they involve more than simple 'measurement'); Collections of body secretions by non-invasive methods, venepuncture (taking of a blood sample), or asking participants to consume foods and/or nutrients (not including the use of drugs or other food supplements or caffine).
Yes

Email confirming Bangor University School of Psychology Ethical Approval

From: e.mcquarrie@bangor.ac.uk

Date: 20/04/2015

Dear Neil,

2015-15008 Growing Kind Minds: A feasibility study and preliminary trial of adapted group-based Compassion Focused Therapy for people with Intellectual Disabilities (CFT-ID)

Your research proposal number 2015-15008
has been reviewed by the Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Confirmation of Bangor University Liability Insurance

QBE European Operations

CERTIFICATE OF EMPLOYERS' LIABILITY INSURANCE (a)

(Where required by regulation 5 of the Employers' Liability (Compulsory Insurance) Regulations 1998 (the Regulations), one or more copies of this certificate must be displayed at each place of business at which the policy holder employs persons covered by the policy)

1. Name of policy holder
Bangor University

Policy No **Y016458QBE0114A / 026**

2. Date of commencement of insurance policy **1st August 2014**

3. Date of expiry of insurance policy **31st July 2015**

We hereby certify that subject to paragraph 2:

1. the policy to which this certificate relates satisfies the requirements of the relevant law applicable in Great Britain, Northern Ireland, Isle of Man, Island of Jersey, Island of Guernsey, Island of Alderney; or any offshore installations in territorial waters around Great Britain and its Continental Shelf **(b)**: and;

2. (a) the minimum amount of cover provided by this policy is no less than £5 million **(c)**; or

~~(b) the cover provided under this policy relates to claims in excess of [£] but not exceeding [£].~~

3. the policy covers the holding company and all its subsidiaries

Signed on behalf of QBE Insurance (Europe) Limited (Authorised Insurer)

Notes

(a) *Where the employer is a company to which regulation 3(2) of the Regulations applies, the certificate shall state in a prominent place, either that the policy covers the holding company and all its subsidiaries, or that the policy covers the holding company and all its subsidiaries except any specifically excluded by name, or that the policy covers the holding company and only the named subsidiaries.*

(b) *Specify applicable law as provided for in regulation 4(6) of the Regulations.*

(c) *See regulation 3(1) of the Regulations and delete whichever of paragraphs 2(a) or 2(b) does not apply. Where 2(b) is applicable, specify the amount of cover provided by the relevant policy.*

Important

The Employers' Liability (Compulsory Insurance) Regulations 1998 requires that you keep this certificate or a copy for at least 40 years. Extra copies of the certificate will by supplied upon request.

QBE Insurance (Europe) Limited, Plantation Place, 30 Fenchurch Street, London, EC3M 3BD - Registered in England No. 1761561
Authorised and Regulated by the Financial Services Authority – Registration Number 202842

NHS REC Ethics Proposal: IRAS form

NHS REC Form | Reference: 15/WA/0226 | IRAS Version 4.0.0

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Adapted group-based CFT for people with Intellectual Disabilities V2

1. Is your project research?

(•) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
(•) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
( ) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Will the study involve the use of any medical device without a CE Mark, or a CE marked device which has been modified or will be used outside its intended purposes?

( ) Yes (•) No

2b. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(•) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(•) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(•) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- [ ] England
- [ ] Scotland
- [x] Wales
- [ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ○ England
- ○ Scotland
- ◉ Wales
- ○ Northern Ireland
- ○ This study does not involve the NHS

4. Which review bodies are you applying to?

- [x] NHS/HSC Research and Development offices
- [ ] Social Care Research Ethics Committee
- [x] Research Ethics Committee
- [ ] Confidentiality Advisory Group (CAG)
- [ ] National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

(●) Yes ( ) No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

( ) Yes (●) No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

( ) Yes (●) No

Integrated Research Application System
Application Form for Other clinical trial or investigation

NHS Health Research Authority

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Adapted group-based CFT for people with Intellectual Disabilities V2

Please complete these details after you have booked the REC application for review.

REC Name:
Wales REC 5

REC Reference Number:
15/WA/0226

Submission date:
04/06/2015

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Growing Kind Minds: A feasibility study and preliminary trial of adapted group-based Compassion Focused Therapy for people with Intellectual Disabilities (CFT-ID)

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title	Forename/Initials	Surname
Mr	Neil	Clapton

Address	North Wales Clinical Psychology Programme Brigantia Building, Bangor University Bangor, Gwynedd
Post Code	LL57 2DG
E-mail	psp2d9@bangor.ac.uk
Telephone	07825542644
Fax	

Give details of the educational course or degree for which this research is being undertaken:
Name and level of course/ degree:
DClinPsy

Name of educational establishment:
Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Professor	Robert	Jones
Address	Programme Director, North Wales Clinical Psychology Programme		
	School of Psychology, Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2AS		
E-mail	r.s.jones@bangor.ac.uk		
Telephone	01248 382627		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Mr Neil Clapton	☑ Professor Robert Jones

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- ◉ Student
- ○ Academic supervisor
- ○ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Mr	Neil	Clapton
Post	Trainee Clinical Psychologist		
Qualifications	BSc (Hons) Psychology		
Employer	NHS		
Work Address	North Wales Clinical Psychology Programme		
	Brigantia Building, Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2DG		
Work E-mail	psp2d9@bangor.ac.uk		

* Personal E-mail	neil_clapton@yahoo.co.uk
Work Telephone	07825542644
* Personal Telephone/Mobile	07825542644
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Mr	Hefin	Francis
Address	School of Psychology		
	Brigantia Building, Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2AS		
E-mail	h.franics@bangor.ac.uk		
Telephone	01248388339		
Fax	01248382599		

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	
Sponsor's/protocol number:	2015-15008
Protocol Version:	LSRP V1
Protocol Date:	13/04/2015
Funder's reference number:	
Project website:	

Registry reference number(s):
The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that "every clinical trial must be registered on a publicly accessible database before recruitment of the first subject"; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.

International Standard Randomised Controlled Trial Number (ISRCTN):
ClinicalTrials.gov Identifier (NCT number):

Additional reference number(s):

Ref.Number Description	Reference Number

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Compassion Focused Therapy (CFT) is a particular therapeutic approach originally designed for people who are highly self-critical and experience feelings of shame. These processes play key roles across mental health difficulties, including depression and anxiety. There is evidence that people with Intellectual Disabilities (ID) can experience such shame-based difficulties. Cultivating self-compassion can act as a shame antidote and reduce self-criticism, and have positive effects on mood/well-being. Whilst there is growing evidence for compassion-based interventions in adult clinical populations, there is little availability of such interventions for adult individuals with an Intellectual Disability.

The aim of this study is to undertake a preliminary pilot of an adapted CFT group for individuals with an Intellectual Disability and co-ocurring mental health difficulties, to determine its feasibility with this population and establish preliminary efficacy. It is expected that teaching self-compassion through six sessions of a CFT group will reduce psychological distress and improve psychological well-being.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

In developing this proposal, formal and informal consultation has been sought from the original creator of Compassion Focused Therapy (CFT), Professor Paul Gilbert OBE, and a number of other experts in the CFT community who have either extensive experience of running CFT groups or work with individuals/groups with Intellectual Disabilities (ID).

Several psychometric measures have also had to be specifically adapted and tailored to be made understandable, accessible and meaningful to individuals who have an Intellectual Disability. This includes the Self-Compassion Scale-Short Form, of which permission has been obtained and granted to use and adapt from the original author (Kristin Neff). These measures have/will have been run by a Speech and Language Therapist (SALT), and a service-user consult to test out face validity.

The main ethical issues emanating from this research relate to the potential capacity to consent to inclusion and treatment. This has been addressed by the creation of a rigorous capacity assessment protocol, based on previous related research into the capacity of individuals with an Intellectual Disability to consent to inclusion in research (Arscott et al, 1998; Bernal, 2006; Cameron & Murphy, 2007; Fisher et al, 2006; McDonald & Kidney, 2012). This assessment includes multiple sources and raters to corroborate any decision relating to capacity. To further enable and ensure this process, study information and consent forms shall be presented in an easy-read format that best allows individuals with an ID to make an informed decision. The study will ONLY include participants who have been demonstrated to have the capacity to consent.

Other potential issues pertain to potential drop-out, and thus having insufficient data to conduct a reasonable analysis of initial efficacy of the intervention. For this reason, a minimum of two groups shall be run in order to obtain sufficient participant numbers. Additionally, the group shall be open to referrals across all Learning Disability teams in North Wales, to ensure equality of access to the intervention and adequate referral numbers.

There is some small risk that some participants may become mildly distressed when engaging in practices to cultivate self-compassion, relating to fears/blocks/resistances to compassion as identified in previous research (Gilbert et al; 2011, 2012, 2014; Pauley & McPherson, 2010; Rockliff et al, 2008). However, CFT was specifically developed to explicitly address this issue, and includes a number of therapeutic processes and procedures to formally address these issues (Gilbert; 2010, 2014; Duarte et al, 2014). This shall be an integral part of the intervention and incorporated into each group session, to ensure that any distress is appropriately identifed, addressed, and resolved.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☑ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☐ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

Is a group-based adapted compassion-focused intervention feasible, acceptable and efficacious for individuals with an Intellectual Disability (ID) who have concurrent Mental Health issues?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Does teaching self-compassion to people with ID reduce psychological distress and improve psychological well-being?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

The role of shame, related social comparison, self-criticism and its contribution to and maintenance of depression and anxiety in those with ID is relatively neglected and not always specifically targeted in interventions. Research suggests that developing and adapting psychological interventions that explicitly and directly work with shame, related social comparison and self-worth, may be a promising avenue in reducing psychological distress and improving the well-being of individuals with ID. Compassion Focused Therapy (CFT; Gilbert, 2005, 2009, 2010) is one such promising approach, as it was specifically developed for people with mental health difficulties characterised by high shame and self-criticism.

Previous research has attempted to teach self-compassion to adult individuals with ID with recurrent depression and anxiety, but within the context of an adapted Mindfulness-Based Cognitive Therapy group intervention (Idusohan-Moizer et al, 2013). Whilst this appeared to be relatively successful, evidenced by significant increases in compassion for self and other, and reductions in anxiety and depression, this was not the primary focus of the intervention. This renders it more difficult to tease out the specific effects of the self-compassion component of this intervention.

To date, no known study has formally adapted Compassion Focused Therapy (CFT), its principle components, and related practices of Compassionate Mind Training (CMT; Gilbert & Irons, 2005; Gilbert & Procter, 2006) for individuals with Intellectual Disability, and/or investigated whether this is feasible and acceptable in a group format for this population. Equally, adults with an ID should arguably have the same access to interventions that are available for other populations if they are deemed to be equally efficacious.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

The study is looking to recruit participants whom are open to the NHS Community Learning Disabilities Teams in/across North Wales. This will involve visiting teams to explain to them the nature of the study, whom maybe suitable candidates, discuss inclusion/exclusion criteria, and thus encourage team members to identify and refer potentially suitable candidates. Criterion for referral will consist of the following:

(1) Diagnosis of a Learning Disability
(2) Significant psychological distress, as measured by the PTOS-ID II (Beail, in press)
(3) Demonstrate self-criticism and low/moderate self-compassion, as indicated by the Self-Compassion Scale-Short Form (Raes et al, 2011)
(3) Participants MUST have the capacity to consent

Participants will be initially approached by their primary healthcare professional, where they will be informed about the nature of the group. If they express an interest and informally agree, they will be invited to a pre-group assessment session with the primary investigator, where they will be invited to participate in the study and be offered the opportunity to ask any questions. Written (and/or verbal) consent will be sought from participants who agree to attend the group and allow their data to be used in the study. Participants will be informed of their right to withdraw at any time, as well as their right to withdraw their data for use in the study. If capacity to consent is established and informed consent is obtained, participants will be invited to complete the relevant psychometric measures (see below) before attending the group. They will be offered the opportunity to either complete the measures there-and-then, or at an agreed later date. The whole initial assessment process is anticipated to last no longer than one to one and a half hours.

Psychometric Measures/Assessments

Self-Compassion
The Self-Compassion Scale-Short Form (Raes et al, 2011) is a shortened 12-item version of the original 26-item Self-Compassion Scale (Neff, 2003), a measure designed to assess an individual's self-compassion across three components: self-kindness, common humanity, and mindfulness. The original Self-Compassion Scale (SCS) has demonstrated good psychometric properties, with the Short-Form SCS demonstrating a near perfect correlation with the long form SCS ($r \geq 0.97$ all samples), and adequate internal consistency (Cronbach's alpha ≥ 0.86 in all samples). This measure has yet to be validated or adequately applied to research within the population of Intellectual Disability. Permission has been obtained from the author to adapt the scale for the identified population.

Psychological Distress and Well-Being (Anxiety and Depression)
The Psychological Therapy Outcome Scale for Intellectual Disabilities 2nd Edition (PTOS-ID II; Beail, in press) measures both psychological distress (encompassing anger, anxiety, and depression) and psychological well-being, which lends itself more favourably as a scale that is both accessible and meaningful to this population. The scale has both a self-report and corresponding carer-report version.

Shame-related Measures
The Social Comparison Scale (Allen & Gilbert, 1995) examines the way people evaluate themselves through comparisons with others, and is often used in research as an indicator of internal shame. It has been successfully adapted for use with individuals with mild to moderate intellectual disabilities (Dagnan & Sandhu, 1999). The adapted version has demonstrated good psychometric properties such as factor structure and concurrent validity with the original scale (Dagnan & Sandhu, 1999), with a reasonable Cronbach's alpha for the full-scale with this population (Paterson et al, 2012).

Participants will thus be required to attend the six group sessions, each of which will last approximately 1-1.5 hours and require some home/personal practice.

On completion of the group, participants will be required to attend a post-group assessment session where they will be required to complete the same measures administered pre-group. This may also involve the completion of a post-group evaluation form or semi-structured interview. This is not expected to take longer than one hour. In order to further supplement the data on feasibility and acceptability, a feedback questionnaire pertaining to these outcomes will also be administered at the end of every group session.

Data Analysis
The statistical software package SPSS will be used to analyse the collated data. Data analysis is likely to include a number of within group comparisons for scores obtained at various time points (e.g. pre-group and post-group), utilising t-tests to compare mean scores (where data is normally distributed, or non-parametric equivalent where this is not the case) and appropriate effect size analysis. Any semi-structured interviews or focus groups are likely to be analysed utilising deductive thematic analysis, in accordance with suggestions by Braun & Clarke (2006).

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [ ] Management of the research
- [ ] Undertaking the research
- [ ] Analysis of results
- [ ] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
This involves consultation with a service-user(s) around the development/refinement of psychometric instruments, group material and resources, and presentation of concepts within the group (to assess if presented at the 'correct' level of understanding/comprehension, accessibility etc).

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Participants must meet the following principal inclusion criteria:
(1) Have a diagnosis of an Intellectual Disability
(2) Male and female, aged 18+ (no upper age limit)
(3) Experience significant psychological distress (as indicated by the PTOS-ID II) that may/may not encompass anxiety and/or low mood, and accompanying self-criticism (as indicated by appropriate measures and behavioural observations)
(4) Participants MUST have capacity to consent

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Exclusion criteria encompass the following:
(1) Participants who are under the age of 18
(2) Participants who are actively psychotic or experiencing mania
(3) Participants who lack the capacity to provide informed consent

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Participant approached regarding	1	0	15 minutes	Initially approached by lead clinician/healthcare professional as regards potential interest.

potential involvement in group & study				
Consent - assess capacity & obtain informed consent	1	0	15 minutes	Principal investigator to explain group/study and provide with relevant information, obtain informed consent, preferably in presence of carer/lead healthcare professional to corroborate capacity.
Pre-group Assessment	1	0	45 minutes	Assessment undertaken by Principal investigator. Will involve administration and completion of all relevant psychometric measures, including: PTOS ID-II, Self-Compassion Scale, Social Comparison Scale. Assessment process should take no longer than 1 hour, and will be completed at a convenient time, date and location for the participant.
Post-group Assessment	1	0	1 hour	Assessment undertaken by Principal investigator. Will involve administration and completion of all relevant psychometric measures, including: PTOS ID-II, Self-Compassion Scale, Social Comparison Scale. Assessment process should take no longer than 1 hour, and will be completed at a convenient time, date and location for the participant.
Evaluation session	1	0	1 hour	Focus group/semi-structured interview session to be conducted by a Trainee Clinical Psychologist within the Learning Disabilities Service.

A19. Give details of any clinical intervention(s) or procedure(s) to be received by participants as part of the research protocol. *These include uses of medicinal products or devices, other medical treatments or assessments, mental health interventions, imaging investigations and taking samples of human biological material. Include procedures which might be received as routine clinical care outside of the research.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days).
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
CFT group - 6 sessions	6	0	6-9 hours	Principal Investigator and supervisor to facilitate running of group sessions. Group shall be run at a location that is easily and readily accessible for the majority of participants.

A20. Will you withhold an intervention or procedure, which would normally be considered a part of routine care?

○ Yes ◉ No

A21. How long do you expect each participant to be in the study in total?

The approximate duration of the study will be 18 months from start to completion. However, from the obtaining of informed consent, participants can expect to be actively involved from pre to post-group assessment for approximately 3-4 months. The majority of this time will involve attending a 1-1.5 hour group session once a week, which will take 6 weeks to complete. The amount of total time participants will actively have to devote to the study will be approximately 9-12 hours.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

In terms of the assessment process, there is some small risk that some participants may find some of the questions

mildly distressing, as they are of a potentially emotive nature. However, most of the questionnaires have been routinely and safely used as assessments with individuals with Intellectual Disabilities. Prior to starting the assessment process, the principal investigator shall establish with the participant an agreed way of communicating if they are distressed. Should this happen, the principal investigator shall halt the assessment process and address the immediate distress, and subsequently ascertain whether the participant wishes to continue or not. If not, the participant shall be directed to further appropriate support if required. The principal investigator will contact the participants lead clinician and GP, with the participants consent, to inform them about the participants' current situation.

In terms of the intervention, there is some small risk that some participants may become mildly distressed when engaging in practices to cultivate self-compassion, relating to fears/blocks/resistances to compassion as identified in previous research (Gilbert et al; 2011, 2012, 2014; Pauley & McPherson, 2010; Rockliff et al, 2008). However, CFT was specifically developed to explicitly address this issue, and includes a number of therapeutic processes and procedures to formally address these issues (Gilbert; 2010, 2014; Duarte et al, 2014). This shall be an integral part of the intervention and incorporated into each group session, to ensure that any distress is appropriately identified, addressed, and resolved.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

◉ Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

Due to the nature of the measures being used to assess anxiety, depression, and shame/stigma, there is some small risk that some participants may find some of the questions mildly distressing, as they are of a potentially emotive nature. However, most of the questionnaires have been routinely and safely used as assessments with individuals with Intellectual Disabilities.Should this happen, the principal investigator shall halt the assessment process and address the immediate distress, and subsequently ascertain whether the participant wishes to continue or not. If not, the participant shall be directed to further appropriate support if required. The principal investigator will contact the participants lead clinician, with the participants consent, to inform them about the participants' current situation (a letter has been pre-devised should this eventuality arise).

There is some small possibility that during any phase of the study participants may make disclosures around abuse. The limits of confidentiality shall be explicitly set out and agreed before and when obtaining consent. A protocol outlining the process(es) to manage incidental disclosures has been attached to the application.

A24. What is the potential for benefit to research participants?

A recent systematic review has elucidated early evidential findings related to the possible psychotherapeutic benefits of Compassion Focused Therapy for a number of clinical populations (Leaviss & Uttley, 2014). This adds to the extant research on the numerous benefits of cultivating compassion/self-compassion, in terms of reduced psychological/emotional distress, increased psychological resilience and well-being (Gilbert & Proctor, 2006; Leary et al, 2007; Hofmann et al, 2011; Neff, 2011; Barnard & Curry, 2011; Van Dam et al, 2011; Macbeth & Gumley, 2012).

Furthermore, previous research has attempted to teach self-compassion to adult individuals with ID with recurrent depression and anxiety, but within the context of an adapted Mindfulness-Based Cognitive Therapy group intervention (Idusohan-Moizer et al, 2013). Whilst this appeared to be relatively successful, evidenced by significant increases in compassion for self and other, and reductions in anxiety and depression, this was not the primary focus of the intervention. This renders it more difficult to tease out the specific effects of the self-compassion component of this intervention.

This intervention shall build on these preliminary findings by explicitly cultivating self-compassion to address shame, related social comparison, and self-criticism in adults with ID, as these processes can contribute to and maintain depression and anxiety in those with ID. This study will give individuals access to a potentially powerful psychotherapeutic intervention which is as of yet not fully adapted or readily accessible to individuals with ID.

A25. What arrangements are being made for continued provision of the intervention for participants, if appropriate, once the research has finished? *May apply to any clinical intervention, including a drug, medical device, mental health intervention, complementary therapy, physiotherapy, dietary manipulation, lifestyle change, etc.*

The study plans to provide a potential parallel one-off session for carers and involved healthcare professionals to

understand the CFT model, processes and principal components, and how to assist individuals they care for/work with practice self-compassion in daily life (e.g. complete personal practice between groups).

A26. What are the potential risks for the researchers themselves? *(if any)*

The principal investigator may sometimes be conducting the assessments alone, and therefore should follow the NHS lone worker policy. There are no foreseen significant risks for the researcher.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Participants will be recruited from those individuals open to the NHS Community Learning Disabilities Teams in North Wales. The nature and aims of the study will be discussed within appropriate multidisciplinary team meetings, and team members will be encouraged to identify and refer potentially suitable candidates that meet the inclusion criteria. All identification will therefore be made through members of the direct care team(s).

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Participants will be first approached by their lead professional/key worker to guage potential interest in participating in the group and research. Potential participants will then be approached by the principal investigator to more fully explain the nature of the group and study.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Participants will be invited by the principal investigator to a pre-group session with their carer or primary healthcare professional (optional). They will be informed about the nature of the group, provided with a written participant information sheet, and will be invited to participate in the study and be offered the opportunity to ask any questions. They will also be given the option to have some time to consider their potential involvement. Written consent will be sought from participants who agree to attend the group and allow their data to be used in the study. Participants will be informed of their right to withdraw at any time, as well as their right to withdraw their data for use in the study. If capacity to consent is established and informed consent is obtained, paritcpants will be invited to complete the relevant psychometric measures before attending the group.

A rigorous capacity assessment protocol has been developed, based on previous related research into the capacity of individuals with an Intellectual Disability to consent to inclusion in research (Arscott et al, 1998; Bernal, 2006; Cameron & Murphy, 2007; Fisher et al, 2006; McDonald & Kidney, 2012). This assessment includes multiple sources and raters to corroborate any decision relating to capacity. To further enable and ensure this process, study information and consent forms shall be presented in an easyread format that best allows individuals with an ID to make an informed decision.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

(●) Yes ( ) No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will be given ample time to reflect on and discuss the information presented, and/or discuss it with someone they trust. Whilst ideally participants will make a decision there-and-then when approached by the principal investigator, they will be given the option of having a specified time period (e.g. a week) to make an informed decision (the principal investigator in this instance would agree to return and re-assess capacity to provide informed consent). The participant information sheet will also highlight that they may change their mind and withdraw from the study at any time.

A32. Will you recruit any participants who are involved in current research or have recently been involved in any research prior to recruitment?

( ) Yes
(●) No
( ) Not Known

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

All participant information sheets and consent forms shall be presented in an easy-read manner with appropriate visual supports. Where appropriate, steps will be taken for participants to indicate their responses in a non-verbal manner (e.g. using visual supports). If there is any doubt about a participant's ability to understand the information or communicate that they have fully understood the information presented, capacity to consent shall not be assumed and they will not be included in the study.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

Given that the population is located in North Wales, every attempt will be made to accommodate individuals who are Welsh First Language speakers. This will include the availability of any prior consent forms and related material in Welsh (and a Welsh speaker to convey information), and (if possible) the translation of group materials into Welsh.

A34. What arrangements will you make to ensure participants receive any information that becomes available during the course of the research that may be relevant to their continued participation?

Participants shall be regularly approached at the end of group sessions to assess their level of understanding of information and concepts presented in the group, and any specific difficulties they maybe experiencing within sessions. This will also provide an opportunity to monitor continued capacity to consent.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

◉ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☐ Use of audio/visual recording devices
- ☑ Storage of personal data on any of the following:
  - ☑ Manual files including X-rays
  - ☑ NHS computers
  - ☐ Home or other personal computers
  - ☐ University computers
  - ☐ Private company computers
  - ☐ Laptop computers

Further details:
The required paper data will be securely kept separately from participant's notes/files, locked in a designated file drawer in the relevant base/premises. Any electronic data will be anonymised, collated and entered onto a database within the appropriate premises to ensure the security of the patient's files. No identifiable information will leave the premises. The anonymised electronic data will be stored on an encrypted device to further ensure security. This data will be kept by the NWCCP until the elapsing of a specified time period. The collated data will be completely anonymised and stored securely in accordance with the Data Protection Act.

Any data collected or recorded through the means of a potential semi-structured interviews shall be stored in a similar manner, with any recorded data being erased immediately after its transcription. Any data collected in this manner shall be anonymised to prevent personal identification and ensure confidentiality. Devices such as Dictaphones, and all electronic/related data encrypted on a SafeStick, shall be securely locked in a box, and will be brought to and from

base (if required) in a locked box/cabinet.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

See above A36

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

No other individuals or parties outside the direct care team will have access to participants' personal data.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- (●) Less than 3 months
- ( ) 3 – 6 months
- ( ) 6 – 12 months
- ( ) 12 months – 3 years
- ( ) Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

( ) Yes (●) No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

( ) Yes (●) No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

( ) Yes (●) No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

(●) Yes ( ) No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?

◉ Yes ○ No

It should be made clear in the participant's information sheet if the GP/health professional will be informed.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that "every clinical trial must be registered on a publicly accessible database before recruitment of the first subject"; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.

○ Yes ◉ No

Please give details, or justify if not registering the research.
This is not the type of research suitable for registration on a public database. However, all research conducted at Bangor University forms part of the university's repository, which is publicly accessible.

Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- ☑ Peer reviewed scientific journals
- ☑ Internal report
- ☑ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

A53. Will you inform participants of the results?

◉ Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Feedback of the results will be offered to all parties involved in the study. Participants will be offered the choice of which method (one-to-one session, letter, telephone call) they would like to receive the feedback, if any. Preference shall be sought at the stage of initial consent.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- ☐ Independent external review
- ☐ Review within a company
- ☐ Review within a multi−centre research group
- ☑ Review within the Chief Investigator's institution or host organisation

☑ Review within the research team
☑ Review by educational supervisor
☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The current research proposals has been submitted to the NWCPP research department to be assessed and approved. The principle investigator has received approval from the NWCPP research department.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? *Tick as appropriate:*

☐ Review by independent statistician commissioned by funder or sponsor
☐ Other review by independent statistician
☐ Review by company statistician
☑ Review by a statistician within the Chief Investigator's institution
☑ Review by a statistician within the research team or multi−centre group
☑ Review by educational supervisor
☐ Other review by individual with relevant statistical expertise
☐ No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title	Forename/Initials	Surname
	Dr	Gemma	Griffith
Department	North Wales Clinical Psychology Programme (NWCPP) Research Department		
Institution	Bangor University		
Work Address	North Wales Clinical Psychology Programme (NWCPP)		
	Bangor University		
	Bangor		
Post Code	LL57 2DG		
Telephone	01248388365		
Fax	01248383718		
Mobile			
E-mail	g.m.griffith@bangor.ac.uk		

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

The primary outcome measure will be changes in overall psychological distress and well-being, as measured by the PTOS-ID II (referring to relevant clinical cut-offs).

A58. What are the secondary outcome measures? *(if any)*

The secondary outcome measures will be changes in overall level self-compassion, social comparison, and shame, as measured by the Self-Compassion Scale-Short Form and Social Comparison Scale.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 20
Total international sample size (including UK):
Total in European Economic Area:

Further details:
A minimum of two groups (no more than three) shall be run to ensure there are adequate numbers of participants and data to conduct a meaningful analysis.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The sample size for the research has been based on the running of related previous groups to obtain adequate and meaningful data for analysis (Idusohan-Moizer et al, 2013).

A61. Will participants be allocated to groups at random?

○ Yes ◉ No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The statistical software package SPSS will be used to analyse the collated data. Data analysis is likely to include a number of within group comparisons for scores obtained at various time points (e.g. pre-group and post-group), utilising t-tests to compare mean scores (where data is normally distributed, or non-parametric equivalent where this is not the case), and appropriate effect size analysis.

Any semi-structured interviews will be based on previous interview schedules developed to examine the feasibility and acceptability of CFT groups (Heriot-Maitland et al, 2014), and are likely to be analysed utilising deductive thematic analysis, in accordance with suggestions by Braun & Clarke (2006).

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co−applicants, protocol co−authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Professor	Robert	Jones
Post	Programme Director		
Qualifications	DClinPsy, BSc (Hons) Psychology		
Employer	Bangor University		
Work Address	North Wales Clinical Psychology Programme School of Psychology, Bangor University Bangor, Gwynedd		
Post Code	LL57 2AS		
Telephone	01248 382627		
Fax			
Mobile			
Work Email	r.s.jones@bangor.ac.uk		

	Title	Forename/Initials	Surname
	Dr	Jonathan	Williams
Post	Senior Clinical Psychologist		
Qualifications	DClinPsy, BSc (Hons) Psychology		
Employer	Betsi Cadwaladr University Health Board		
Work Address	Denbighshire Complex Disabilities Team B7, Trem Y Dyffryn, Colomendy Industrial Estate Denbigh, Denbighsire		
Post Code	LL16 5TX		
Telephone	01824 712750		
Fax			
Mobile			
Work Email	jonathan.williams@wales.nhs.uk		

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: ○ NHS or HSC care organisation
◉ Academic
○ Pharmaceutical industry
○ Medical device industry
○ Local Authority
○ Other social care provider (including voluntary sector or private organisation)
○ Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation	School of Psychology, Bangor University
Given name	Hefin
Family name	Francis
Address	School of Psychology, Adeilad Building
Town/city	Bangor
Post code	LL57 2AS
Country	UNITED KINGDOM
Telephone	01248388339
Fax	01248382599
E-mail	h.francis@bangor.ac.uk

Is the sponsor based outside the UK?
○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress
- ☑ No application for external funding will be made

What type of research project is this?

- ○ Standalone project
- ○ Project that is part of a programme grant
- ○ Project that is part of a Centre grant
- ◉ Project that is part of a fellowship/ personal award/ research training award
- ○ Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Dr	Rossela	Roberts
Organisation	Clinical Governance Officer, BCUHB		
Address	Research and Development Office		
	Clinical School		
	Ysbyty Gwynedd		
Post Code	LL57 2PW		
Work Email	rossela.roberts@wales.nhs.uk		
Telephone	01248383877		
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 02/03/2015
Planned end date: 06/06/2016
Total duration:
Years: 1 Months: 3 Days: 5

A71-2. Where will the research take place? *(Tick as appropriate)*

- ☐ England
- ☐ Scotland
- ☑ Wales
- ☐ Northern Ireland
- ☐ Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?
○ Yes ◉ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☐ NHS organisations in England	
☑ NHS organisations in Wales	1
☐ NHS organisations in Scotland	
☐ HSC organisations in Northern Ireland	
☐ GP practices in England	
☐ GP practices in Wales	
☐ GP practices in Scotland	
☐ GP practices in Northern Ireland	
☐ Social care organisations	
☐ Phase 1 trial units	
☐ Prison establishments	
☐ Probation areas	
☐ Independent hospitals	
☐ Educational establishments	
☐ Independent research units	
☐ Other (give details)	
Total UK sites in study:	1

A75-1. What arrangements will be made to review interim safety and efficacy data from the trial? Will a formal data monitoring committee or equivalent body be convened?

No formal procedures or bodies/committees involved; frequent monitoring by academic supervisor will be utilised to review safety and efficacy.

If a formal DMC is to be convened, please forward details of the membership and standard operating procedures to the Research Ethics Committee when available. The REC should also be notified of DMC recommendations and receive summary reports of interim analyses.

A75-2. What are the criteria for electively stopping the trial or other research prematurely?

Lack of attendance and/or significant drop-out from the study.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care

(HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

The study will be insured by Bangor University (indemnity certificate enclosed).

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

See A76-1

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

See A76-1

Please enclose a copy of relevant documents.

A77. Has the sponsor(s) made arrangements for payment of compensation in the event of harm to the research participants where no legal liability arises?

○ Yes ◉ No

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	Betsi Cadwaldr University Health Board	Title	Dr
Department name	Denbighshire Complex Disabilities Team	First name/ Initials	Jonathan
Street address	B7, Trem Y Dyffryn, Colomendy Industrial Estate	Surname	Williams
Town/city	Denbigh		
Post Code	LL16 5TX		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. I understand that the main REC or its operational managers may share information in this application or supporting documentation with the Medicines and Healthcare products Regulatory Agency (MHRA) where it is relevant to the Agency's statutory responsibilities.

12. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further

information. We would be grateful if you would indicate one of the contact points below.

- (•) Chief Investigator
- ( ) Sponsor
- ( ) Study co-ordinator
- ( ) Student
- ( ) Other – please give details
- ( ) None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Mr Neil Clapton on 03/06/2015 18:24.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	BCUHB
Email:	psp2d9@bangor.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Mr Hefin Francis on 04/06/2015 09:06.

Job Title/Post:	School Manager for Psychology
Organisation:	Bangor University
Email:	h.francis@bangor.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Professor Robert Jones on 03/06/2015 18:46.

Job Title/Post:	Programme Director
Organisation:	NWCPP
Email:	

North Wales REC Favourable Opinion Letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

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Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Mr Neil Clapton
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
Brigantia Building, Bangor University
Bangor, Gwynedd
LL57 2DG psp2d9@bangor.ac.uk

22 June 2015

Dear Mr Clapton,

Study title:	**Growing Kind Minds: A feasibility study and preliminary trial of adapted group-based Compassion Focused Therapy for people with Intellectual Disabilities (CFT-ID)**
REC reference:	**15/WA/0226**
Protocol number:	**2015-15008**
IRAS project ID:	**184366**

The Research Ethics Committee reviewed the above application at the meeting held on 18 June 2015. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Dr Rossela Roberts, rossela.roberts@wales.nhs.uk
Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

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

The Committee requested that the Participant Information Sheet is revised

The paragraph "What will happen" should include a sentence to detail the need for a focus group or semi-structured interview in the follow-up phase of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net

The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS Sites
The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Social or scientific value; scientific design and conduct of the study
The Committee considered whether the objectives, design, methodology, and the conduct of the study are appropriately described in the protocol and concluded that the research design and the proposed analysis are adequate to answer the research question.
It was noted that this is a re-submission of an application with a previous unfavourable opinion.
The Committee reviewed the revised documentation and concluded that all issues raised in the previous review have been addressed.
The primary outcome measure reflects the feasibility nature of the study and is assessing acceptability/feasibility of the intervention.
A description of the compassion-focused therapy and associated delivery protocol for this intervention has been included.

Favourable risk benefit ratio; anticipated benefit/risks for research participants
The Committee discussed the anticipated benefits and potential risks to participants and was satisfied that the applicant has suitably identified the risks and benefits and highlighted them in the information given to potential participants.
The Committee noted that the revised protocol now includes a description of the process to manage distress and incidental disclosures.

Informed Consent process and the adequacy and completeness of participant information
The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. The information is clear as to what the participant consents and there is no inducement or coercion. The Committee agreed that the procedures described in the protocol have been adequately addressed in the Information Sheet.
The Participant Information sheet has been written in lay language accessible to the target group for whom the intervention has been designed; it provides adequate detail about the context and content of the intervention/group meetings.
A query was raised in relation to the consent process for the post-group semi-structured interview/focus group.
You clarified that the interview/focus group will take place after the last group session and all participants will be invited.
The Committee requested that details about the interview/focus group are included in the Participant Information Sheet/Consent Form.

The Chairman thanked you and Dr Williams for your availability to speak to this submission and gave you an opportunity to ask questions. You did not raise any issues.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting

Based on the information provided, the Committee was satisfied with the following aspects of the research:

- Social or scientific value; scientific design and conduct of the study
- Recruitment arrangements and access to health information, and fair participant selection
- Favourable risk benefit ratio; anticipated benefit/risks for research participants
- Care and protection of research participants; respect for participants' welfare and dignity
- Informed consent process

- Suitability of the applicant and supporting staff
- Independent review
- Suitability of supporting information
- Other general issues
- Suitability of the summary of the research

The Committee identified issues with the following aspects of the research:

- Adequacy and completeness of participant information

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
REC Application Form		04 June 2015
Other [Covering letter outlining changes to application]	1	03 June 2015
Research protocol or project proposal	1	15 April 2014
Participant information sheet [Growing Kind Minds group and study]	2	03 June 2015
Participant consent form [Growing Kind Minds group and study]	2	03 June 2015
GP/consultant information sheets or letters [Study Participation]	1	13 April 2015
GP/consultant information sheets or letters [Raising Concerns]	1	13 April 2015
Interview schedules or topic guides for participants	1	13 April 2015
Non-validated questionnaire [Feasibility Acceptability Measure]	1	03 June 2015
Validated questionnaire [PTOS-ID II]		
Validated questionnaire [Self-Compassion Scale-Short form]		
Validated questionnaire [The Social Comparison Scale]		
CFT-ID Group Intervention Protocol	1	03 June 2015
Other [Guidelines for the Functional Assessment of Capacity]	2	03 June 2015
Other [CFT-ID Incidental Disclosure & Undue Distress Protocol]	1	03 June 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Summary CV for Chief Investigator (CI) [Neil Clapton]		13 April 2015

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

No declarations of interest were made in relation to this application

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

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

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/WA/0226	**Please quote this number on all correspondence**

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

Yours sincerely

Rossela Roberts

Dr Philip Wayman White, MBChB, FRCGP
Chair
E-mail: *rossela.roberts@wales.nhs.uk*

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

SL-AR2 After ethical review - research oth

Copy:

Sponsor: Mr Hefin Francis
School of Psychology,
Bangor University,
Penralt Road, Brigantia Building,
Bangor, LL57 2AS h.francis@bangor.ac.uk

R&D Office: Ms Debra Slater
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd, LL57 2PW debra.slater@wales.nhs.uk

Wales Research Ethics Committee 5

Attendance at Committee meeting on 18 June 2015

Committee Members

Name	*Profession*	*Capacity*	*Present*
Dr Karen BE Addy	Clinical Psychologist	Expert	Yes
Dr Swapna Alexander	Consultant Physician	Expert	Yes
Mrs Kathryn Chester	Research Nurse	Expert	No
Ms Geraldine Jenson	Retired College Vice-Principal	Lay +	Yes
Mr Eliezer Lichtenstein	Student	Lay +	No
Dr Mark G Lord	Consultant Pathologist	Expert	Yes
Dr Pamela A Martin-Forbes	NISCHR Research Officer	Expert	No
Dr Paul G Mullins	Reader, MRI Physicist	Lay +	No
Mr Vishwanath Puranik	Associate Specialist ENT Surgeon	Expert	Yes
Mrs Lynn C Roberts	Matron, Emergency Department	Expert	No
Mrs Rachel L Roberts-Jones	Student	Lay +	Yes
Mr David A Rowlands	Retired Development & Monitoring Officer	Lay +	Yes
Dr Jason D Walker	Consultant Anaesthetist (Vice-Chairman)	Expert	No
Dr Philip W White	General Practitioner (Chairman)	Expert	Yes
Ms Sydna A Williams	Lecturer	Lay +	Yes

In attendance

Name	*Position (or reason for attending)*
Dr Rossela Roberts	Clinical Governance Officer / RES Manager

North Wales REC – Acknowledgment of compliance with additional conditions

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

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Wales Research Ethics Committee 5

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Mr Neil Clapton
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
Brigantia Building, Bangor University
Bangor, Gwynedd
LL57 2DG psp2d9@bangor.ac.uk 06 July 2015

Dear Mr Clapton,

Study title: **Growing Kind Minds: A feasibility study and preliminary trial of adapted group-based Compassion Focused Therapy for people with Intellectual Disabilities (CFT-ID)**
REC reference: **15/WA/0226**
Protocol number: **2015-15008**
IRAS project ID: **184366**

Thank you for your letter of 05 July 2015.
I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 22 June 2015.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant information sheet [Growing Kind Minds group and study]	3	03 July 2015
Participant consent form [Growing Kind Minds group and study]	3	03 July 2015

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
REC Application Form		04 June 2015
Other [Covering letter outlining changes to application]	1	03 June 2015
Research protocol or project proposal	1	15 April 2014
Participant information sheet [Growing Kind Minds group and study]	3	03 July 2015
Participant consent form [Growing Kind Minds group and study]	3	03 July 2015
GP/consultant information sheets or letters [Study Participation]	1	13 April 2015
GP/consultant information sheets or letters [Raising Concerns]	1	13 April 2015
Interview schedules or topic guides for participants	1	13 April 2015

(list continues overleaf)

(list continued from previous page)

Document	*Version*	*Date*
Non-validated questionnaire [Feasibility Acceptability Measure]	1	03 June 2015
Validated questionnaire [PTOS-ID II]		
Validated questionnaire [Self-Compassion Scale-Short form]		
Validated questionnaire [The Social Comparison Scale]		
CFT-ID Group Intervention Protocol	1	03 June 2015
Other [Guidelines for the Functional Assessment of Capacity]	2	03 June 2015
Other [CFT-ID Incidental Disclosure & Undue Distress Protocol]	1	03 June 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Summary CV for Chief Investigator (CI) [Neil Clapton]		13 April 2015

You should ensure that the sponsor has a copy of the final documentation for the study.

It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/WA/0226	**Please quote this number on all correspondence**

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

Yours sincerely

Rossela Roberts

RES Manager

E-mail: rossela.roberts@wales.nhs.uk

Copy:

Sponsor: Mr Hefin Francis
School of Psychology,
Bangor University,
Penralt Road, Brigantia Building,
Bangor, LL57 2AS h.francis@bangor.ac.uk

R&D Office: Ms Debra Slater
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd, LL57 2PW debra.slater@wales.nhs.uk

NHS R&D Application Form

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Adapted group-based CFT for people with Intellectual Disabilities V2

1. Is your project research?

(•) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
(•) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
( ) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Will the study involve the use of any medical device without a CE Mark, or a CE marked device which has been modified or will be used outside its intended purposes?

( ) Yes (•) No

2b. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(•) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(•) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(•) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

☐ England
☐ Scotland
☑ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

○ England
○ Scotland
◉ Wales
○ Northern Ireland
○ This study does not involve the NHS

4. Which review bodies are you applying to?

☑ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☑ Research Ethics Committee
☐ Confidentiality Advisory Group (CAG)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

(•) Yes ( ) No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

( ) Yes (•) No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

( ) Yes (•) No

Integrated Research Application System
Application Form for Other clinical trial or investigation

NHS/HSC R&D Form (project information)

Please refer to the Submission and Checklist tabs for instructions on submitting R&D applications.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Adapted group-based CFT for people with Intellectual Disabilities V2

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Growing Kind Minds: A feasibility study and preliminary trial of adapted group-based Compassion Focused Therapy for people with Intellectual Disabilities (CFT-ID)

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title	Forename/Initials	Surname
Mr	Neil	Clapton

Address: North Wales Clinical Psychology Programme
Brigantia Building, Bangor University
Bangor, Gwynedd
Post Code: LL57 2DG
E-mail: psp2d9@bangor.ac.uk
Telephone: 07825542644
Fax:

Give details of the educational course or degree for which this research is being undertaken:
Name and level of course/ degree:
DClinPsy

Name of educational establishment:
Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Professor	Robert	Jones
Address	Programme Director, North Wales Clinical Psychology Programme		
	School of Psychology, Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2AS		
E-mail	r.s.jones@bangor.ac.uk		
Telephone	01248 382627		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Mr Neil Clapton	☑ Professor Robert Jones

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (•) Student
- ( ) Academic supervisor
- ( ) Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Mr	Neil	Clapton
Post	Trainee Clinical Psychologist		
Qualifications	BSc (Hons) Psychology		
Employer	NHS		
Work Address	North Wales Clinical Psychology Programme		
	Brigantia Building, Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2DG		
Work E-mail	psp2d9@bangor.ac.uk		
* Personal E-mail	neil_clapton@yahoo.co.uk		
Work Telephone	07825542644		
* Personal Telephone/Mobile	07825542644		
Fax			

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Mr	Hefin	Francis
Address	School of Psychology		
	Brigantia Building, Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2AS		
E-mail	h.franics@bangor.ac.uk		
Telephone	01248388339		
Fax	01248382599		

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	
Sponsor's/protocol number:	2015-15008
Protocol Version:	LSRP V1
Protocol Date:	13/04/2015
Funder's reference number:	
Project website:	

Registry reference number(s):
The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that "every clinical trial must be registered on a publicly accessible database before recruitment of the first subject"; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.

International Standard Randomised Controlled Trial Number (ISRCTN):
ClinicalTrials.gov Identifier (NCT number):

Additional reference number(s):

Ref.Number Description	Reference Number

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Compassion Focused Therapy (CFT) is a particular therapeutic approach originally designed for people who are highly self-critical and experience feelings of shame. These processes play key roles across mental health difficulties,

including depression and anxiety. There is evidence that people with Intellectual Disabilities (ID) can experience such shame-based difficulties. Cultivating self-compassion can act as a shame antidote and reduce self-criticism, and have positive effects on mood/well-being. Whilst there is growing evidence for compassion-based interventions in adult clinical populations, there is little availability of such interventions for adult individuals with an Intellectual Disability.

The aim of this study is to undertake a preliminary pilot of an adapted CFT group for individuals with an Intellectual Disability and co-ocurring mental health difficulties, to determine its feasibility with this population and establish preliminary efficacy. It is expected that teaching self-compassion through six sessions of a CFT group will reduce psychological distress and improve psychological well-being.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

In developing this proposal, formal and informal consultation has been sought from the original creator of Compassion Focused Therapy (CFT), Professor Paul Gilbert OBE, and a number of other experts in the CFT community who have either extensive experience of running CFT groups or work with individuals/groups with Intellectual Disabilities (ID).

Several psychometric measures have also had to be specifically adapted and tailored to be made understandable, accessible and meaningful to individuals who have an Intellectual Disability. This includes the Self-Compassion Scale-Short Form, of which permission has been obtained and granted to use and adapt from the original author (Kristin Neff). These measures have/will have been run by a Speech and Language Therapist (SALT), and a service-user consult to test out face validity.

The main ethical issues emanating from this research relate to the potential capacity to consent to inclusion and treatment. This has been addressed by the creation of a rigorous capacity assessment protocol, based on previous related research into the capacity of individuals with an Intellectual Disability to consent to inclusion in research (Arscott et al, 1998; Bernal, 2006; Cameron & Murphy, 2007; Fisher et al, 2006; McDonald & Kidney, 2012). This assessment includes multiple sources and raters to corroborate any decision relating to capacity. To further enable and ensure this process, study information and consent forms shall be presented in an easy-read format that best allows individuals with an ID to make an informed decision. The study will ONLY include participants who have been demonstrated to have the capacity to consent.

Other potential issues pertain to potential drop-out, and thus having insufficient data to conduct a reasonable analysis of initial efficacy of the intervention. For this reason, a minimum of two groups shall be run in order to obtain sufficient participant numbers. Additionally, the group shall be open to referrals across all Learning Disability teams in North Wales, to ensure equality of access to the intervention and adequate referral numbers.

There is some small risk that some participants may become mildly distressed when engaging in practices to cultivate self-compassion, relating to fears/blocks/resistances to compassion as identified in previous research (Gilbert et al; 2011, 2012, 2014; Pauley & McPherson, 2010; Rockliff et al, 2008). However, CFT was specifically developed to explicitly address this issue, and includes a number of therapeutic processes and procedures to formally address these issues (Gilbert; 2010, 2014; Duarte et al, 2014). This shall be an integral part of the intervention and incorporated into each group session, to ensure that any distress is appropriately identifed, addressed, and resolved.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study

- ☐ Database analysis
- ☐ Epidemiology
- ☑ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☐ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

Is a group-based adapted compassion-focused intervention feasible, acceptable and efficacious for individuals with an Intellectual Disability (ID) who have concurrent Mental Health issues?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Does teaching self-compassion to people with ID reduce psychological distress and improve psychological well-being?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

The role of shame, related social comparison, self-criticism and its contribution to and maintenance of depression and anxiety in those with ID is relatively neglected and not always specifically targeted in interventions. Research suggests that developing and adapting psychological interventions that explicitly and directly work with shame, related social comparison and self-worth, may be a promising avenue in reducing psychological distress and improving the well-being of individuals with ID. Compassion Focused Therapy (CFT; Gilbert, 2005, 2009, 2010) is one such promising approach, as it was specifically developed for people with mental health difficulties characterised by high shame and self-criticism.

Previous research has attempted to teach self-compassion to adult individuals with ID with recurrent depression and anxiety, but within the context of an adapted Mindfulness-Based Cognitive Therapy group intervention (Idusohan-Moizer et al, 2013). Whilst this appeared to be relatively successful, evidenced by significant increases in compassion for self and other, and reductions in anxiety and depression, this was not the primary focus of the intervention. This renders it more difficult to tease out the specific effects of the self-compassion component of this intervention.

To date, no known study has formally adapted Compassion Focused Therapy (CFT), its principle components, and related practices of Compassionate Mind Training (CMT; Gilbert & Irons, 2005; Gilbert & Procter, 2006) for individuals with Intellectual Disability, and/or investigated whether this is feasible and acceptable in a group format for this population. Equally, adults with an ID should arguably have the same access to interventions that are available for other populations if they are deemed to be equally efficacious.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

The study is looking to recruit participants whom are open to the NHS Community Learning Disabilities Teams in/across North Wales. This will involve visiting teams to explain to them the nature of the study, whom maybe suitable candidates, discuss inclusion/exclusion criteria, and thus encourage team members to identify and refer potentially suitable candidates. Criterion for referral will consist of the following:

(1) Diagnosis of a Learning Disability
(2) Significant psychological distress, as measured by the PTOS-ID II (Beail, in press)
(3) Demonstrate self-criticism and low/moderate self-compassion, as indicated by the Self-Compassion Scale-Short Form (Raes et al, 2011)
(3) Participants MUST have the capacity to consent

Participants will be initially approached by their primary healthcare professional, where they will be informed about the nature of the group. If they express an interest and informally agree, they will be invited to a pre-group assessment session with the primary investigator, where they will be invited to participate in the study and be offered the opportunity to ask any questions. Written (and/or verbal) consent will be sought from participants who agree to attend the group and allow their data to be used in the study. Participants will be informed of their right to withdraw at any time, as well as their right to withdraw their data for use in the study. If capacity to consent is established and informed consent is obtained, participants will be invited to complete the relevant psychometric measures (see below) before attending the group. They will be offered the opportunity to either complete the measures there-and-then, or at an agreed later date. The whole initial assessment process is anticipated to last no longer than one to one and a half hours.

Psychometric Measures/Assessments

Self-Compassion
The Self-Compassion Scale-Short Form (Raes et al, 2011) is a shortened 12-item version of the original 26-item Self-Compassion Scale (Neff, 2003), a measure designed to assess an individual's self-compassion across three components: self-kindness, common humanity, and mindfulness. The original Self-Compassion Scale (SCS) has demonstrated good psychometric properties, with the Short-Form SCS demonstrating a near perfect correlation with the long form SCS ($r \geq 0.97$ all samples), and adequate internal consistency (Cronbach's alpha ≥ 0.86 in all samples). This measure has yet to be validated or adequately applied to research within the population of Intellectual Disability. Permission has been obtained from the author to adapt the scale for the identified population.

Psychological Distress and Well-Being (Anxiety and Depression)
The Psychological Therapy Outcome Scale for Intellectual Disabilities 2nd Edition (PTOS-ID II; Beail, in press) measures both psychological distress (encompassing anger, anxiety, and depression) and psychological well-being, which lends itself more favourably as a scale that is both accessible and meaningful to this population. The scale has both a self-report and corresponding carer-report version.

Shame-related Measures
The Social Comparison Scale (Allen & Gilbert, 1995) examines the way people evaluate themselves through comparisons with others, and is often used in research as an indicator of internal shame. It has been successfully adapted for use with individuals with mild to moderate intellectual disabilities (Dagnan & Sandhu, 1999). The adapted version has demonstrated good psychometric properties such as factor structure and concurrent validity with the original scale (Dagnan & Sandhu, 1999), with a reasonable Cronbach's alpha for the full-scale with this population (Paterson et al, 2012).

Participants will thus be required to attend the six group sessions, each of which will last approximately 1-1.5 hours and require some home/personal practice.

On completion of the group, participants will be required to attend a post-group assessment session where they will be required to complete the same measures administered pre-group. This may also involve the completion of a post-group evaluation form or semi-structured interview. This is not expected to take longer than one hour. In order to further supplement the data on feasibility and acceptability, a feedback questionnaire pertaining to these outcomes will also be administered at the end of every group session.

Data Analysis
The statistical software package SPSS will be used to analyse the collated data. Data analysis is likely to include a number of within group comparisons for scores obtained at various time points (e.g. pre-group and post-group), utilising t-tests to compare mean scores (where data is normally distributed, or non-parametric equivalent where this is not the case) and appropriate effect size analysis. Any semi-structured interviews or focus groups are likely to be analysed utilising deductive thematic analysis, in accordance with suggestions by Braun & Clarke (2006).

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [ ] Management of the research
- [ ] Undertaking the research
- [ ] Analysis of results

☐ Dissemination of findings
☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
This involves consultation with a service-user(s) around the development/refinement of psychometric instruments, group material and resources, and presentation of concepts within the group (to assess if presented at the 'correct' level of understanding/comprehension, accessibility etc).

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

☐ Blood
☐ Cancer
☐ Cardiovascular
☐ Congenital Disorders
☐ Dementias and Neurodegenerative Diseases
☐ Diabetes
☐ Ear
☐ Eye
☐ Generic Health Relevance
☐ Infection
☐ Inflammatory and Immune System
☐ Injuries and Accidents
☑ Mental Health
☐ Metabolic and Endocrine
☐ Musculoskeletal
☐ Neurological
☐ Oral and Gastrointestinal
☐ Paediatrics
☐ Renal and Urogenital
☐ Reproductive Health and Childbirth
☐ Respiratory
☐ Skin
☐ Stroke

Gender:	Male and female participants
Lower age limit: 18	Years
Upper age limit:	No upper age limit

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Participants must meet the following principal inclusion criteria:
(1) Have a diagnosis of an Intellectual Disability
(2) Male and female, aged 18+ (no upper age limit)

(3) Experience significant psychological distress (as indicated by the PTOS-ID II) that may/may not encompass anxiety and/or low mood, and accompanying self-criticism (as indicated by appropriate measures and behavioural observations)
(4) Participants MUST have capacity to consent

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Exclusion criteria encompass the following:
(1) Participants who are under the age of 18
(2) Participants who are actively psychotic or experiencing mania
(3) Participants who lack the capacity to provide informed consent

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Participant approached regarding potential involvement in group & study	1	0	15 minutes	Initially approached by lead clinician/healthcare professional as regards potential interest.
Consent - assess capacity & obtain informed consent	1	0	15 minutes	Principal investigator to explain group/study and provide with relevant information, obtain informed consent, preferably in presence of carer/lead healthcare professional to corroborate capacity.
Pre-group Assessment	1	0	45 minutes	Assessment undertaken by Principal investigator. Will involve administration and completion of all relevant psychometric measures, including: PTOS ID-II, Self-Compassion Scale, Social Comparison Scale. Assessment process should take no longer than 1 hour, and will be completed at a convenient time, date and location for the participant.
Post-group Assessment	1	0	1 hour	Assessment undertaken by Principal investigator. Will involve administration and completion of all relevant psychometric measures, including: PTOS ID-II, Self-Compassion Scale, Social Comparison Scale. Assessment process should take no longer than 1 hour, and will be completed at a convenient time, date and location for the participant.
Evaluation session	1	0	1 hour	Focus group/semi-structured interview session to be conducted by a Trainee Clinical Psychologist within the Learning Disabilities Service.

A19. Give details of any clinical intervention(s) or procedure(s) to be received by participants as part of the research protocol. *These include uses of medicinal products or devices, other medical treatments or assessments, mental health interventions, imaging investigations and taking samples of human biological material. Include procedures which might be received as routine clinical care outside of the research.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?

3. Average time taken per intervention/procedure (minutes, hours or days).
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
CFT group - 6 sessions	6	0	6-9 hours	Principal Investigator and supervisor to facilitate running of group sessions. Group shall be run at a location that is easily and readily accessible for the majority of participants.

A20. Will you withhold an intervention or procedure, which would normally be considered a part of routine care?

○ Yes ◉ No

A21. How long do you expect each participant to be in the study in total?

The approximate duration of the study will be 18 months from start to completion. However, from the obtaining of informed consent, participants can expect to be actively involved from pre to post-group assessment for approximately 3-4 months. The majority of this time will involve attending a 1-1.5 hour group session once a week, which will take 6 weeks to complete. The amount of total time participants will actively have to devote to the study will be approximately 9-12 hours.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

In terms of the assessment process, there is some small risk that some participants may find some of the questions mildly distressing, as they are of a potentially emotive nature. However, most of the questionnaires have been routinely and safely used as assessments with individuals with Intellectual Disabilities. Prior to starting the assessment process, the principal investigator shall establish with the participant an agreed way of communicating if they are distressed. Should this happen, the principal investigator shall halt the assessment process and address the immediate distress, and subsequently ascertain whether the participant wishes to continue or not. If not, the participant shall be directed to further appropriate support if required. The principal investigator will contact the participants lead clinician and GP, with the participants consent, to inform them about the participants' current situation.

In terms of the intervention, there is some small risk that some participants may become mildly distressed when engaging in practices to cultivate self-compassion, relating to fears/blocks/resistances to compassion as identified in previous research (Gilbert et al; 2011, 2012, 2014; Pauley & McPherson, 2010; Rockliff et al, 2008). However, CFT was specifically developed to explicitly address this issue, and includes a number of therapeutic processes and procedures to formally address these issues (Gilbert; 2010, 2014; Duarte et al, 2014). This shall be an integral part of the intervention and incorporated into each group session, to ensure that any distress is appropriately identified, addressed, and resolved.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

◉ Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

Due to the nature of the measures being used to assess anxiety, depression, and shame/stigma, there is some small risk that some participants may find some of the questions mildly distressing, as they are of a potentially emotive nature. However, most of the questionnaires have been routinely and safely used as assessments with individuals with Intellectual Disabilities.Should this happen, the principal investigator shall halt the assessment process and address the immediate distress, and subsequently ascertain whether the participant wishes to continue or not. If not, the participant shall be directed to further appropriate support if required. The principal investigator will contact the participants lead clinician, with the participants consent, to inform them about the participants' current situation (a letter has been pre-devised should this eventuality arise).

There is some small possibility that during any phase of the study participants may make disclosures around abuse. The limits of confidentiality shall be explicitly set out and agreed before and when obtaining consent. A protocol outlining the process(es) to manage incidental disclosures has been attached to the application.

A24. What is the potential for benefit to research participants?

A recent systematic review has elucidated early evidential findings related to the possible psychotherapeutic benefits of Compassion Focused Therapy for a number of clinical populations (Leaviss & Uttley, 2014). This adds to the extant research on the numerous benefits of cultivating compassion/self-compassion, in terms of reduced psychological/emotional distress, increased psychological resilience and well-being (Gilbert & Proctor, 2006; Leary et al, 2007; Hofmann et al, 2011; Neff, 2011; Barnard & Curry, 2011; Van Dam et al, 2011; Macbeth & Gumley, 2012).

Furthermore, previous research has attempted to teach self-compassion to adult individuals with ID with recurrent depression and anxiety, but within the context of an adapted Mindfulness-Based Cognitive Therapy group intervention (Idusohan-Moizer et al, 2013). Whilst this appeared to be relatively successful, evidenced by significant increases in compassion for self and other, and reductions in anxiety and depression, this was not the primary focus of the intervention. This renders it more difficult to tease out the specific effects of the self-compassion component of this intervention.

This intervention shall build on these preliminary findings by explicitly cultivating self-compassion to address shame, related social comparison, and self-criticism in adults with ID, as these processes can contribute to and maintain depression and anxiety in those with ID. This study will give individuals access to a potentially powerful psychotherapeutic intervention which is as of yet not fully adapted or readily accessible to individuals with ID.

A25. What arrangements are being made for continued provision of the intervention for participants, if appropriate, once the research has finished? *May apply to any clinical intervention, including a drug, medical device, mental health intervention, complementary therapy, physiotherapy, dietary manipulation, lifestyle change, etc.*

The study plans to provide a potential parallel one-off session for carers and involved healthcare professionals to understand the CFT model, processes and principal components, and how to assist individuals they care for/work with practice self-compassion in daily life (e.g. complete personal practice between groups).

A26. What are the potential risks for the researchers themselves? *(if any)*

The principal investigator may sometimes be conducting the assessments alone, and therefore should follow the NHS lone worker policy. There are no foreseen significant risks for the researcher.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Participants will be recruited from those individuals open to the NHS Community Learning Disabilities Teams in North Wales. The nature and aims of the study will be discussed within appropriate multidisciplinary team meetings, and team members will be encouraged to identify and refer potentially suitable candidates that meet the inclusion criteria. All identification will therefore be made through members of the direct care team(s).

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Participants will be first approached by their lead professional/key worker to guage potential interest in participating in the group and research. Potential participants will then be approached by the principal investigator to more fully explain the nature of the group and study.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Participants will be invited by the principal investigator to a pre-group session with their carer or primary healthcare professional (optional). They will be informed about the nature of the group, provided with a written participant information sheet, and will be invited to participate in the study and be offered the opportunity to ask any questions. They will also be given the option to have some time to consider their potential involvement. Written consent will be sought from participants who agree to attend the group and allow their data to be used in the study. Participants will be informed of their right to withdraw at any time, as well as their right to withdraw their data for use in the study. If capacity to consent is established and informed consent is obtained, pariticpants will be invited to complete the relevant psychometric measures before attending the group.

A rigorous capacity assessment protocol has been developed, based on previous related research into the capacity of individuals with an Intellectual Disability to consent to inclusion in research (Arscott et al, 1998; Bernal, 2006; Cameron & Murphy, 2007; Fisher et al, 2006; McDonald & Kidney, 2012). This assessment includes multiple sources and raters to corroborate any decision relating to capacity. To further enable and ensure this process, study information and consent forms shall be presented in an easyread format that best allows individuals with an ID to make an informed decision.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will be given ample time to reflect on and discuss the information presented, and/or discuss it with someone they trust. Whilst ideally participants will make a decision there-and-then when approached by the principal investigator, they will be given the option of having a specified time period (e.g. a week) to make an informed decision (the principal investigator in this instance would agree to return and re-assess capacity to provide informed consent). The participant information sheet will also highlight that they may change their mind and withdraw from the study at any time.

A32. Will you recruit any participants who are involved in current research or have recently been involved in any research prior to recruitment?

○ Yes

◉ No
○ Not Known

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

All participant information sheets and consent forms shall be presented in an easy-read manner with appropriate visual supports. Where appropriate, steps will be taken for participants to indicate their responses in a non-verbal manner (e.g. using visual supports). If there is any doubt about a participant's ability to understand the information or communicate that they have fully understood the information presented, capacity to consent shall not be assumed and they will not be included in the study.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

Given that the population is located in North Wales, every attempt will be made to accommodate individuals who are Welsh First Language speakers. This will include the availability of any prior consent forms and related material in Welsh (and a Welsh speaker to convey information), and (if possible) the translation of group materials into Welsh.

A34. What arrangements will you make to ensure participants receive any information that becomes available during the course of the research that may be relevant to their continued participation?

Participants shall be regularly approached at the end of group sessions to assess their level of understanding of information and concepts presented in the group, and any specific difficulties they maybe experiencing within sessions. This will also provide an opportunity to monitor continued capacity to consent.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

◉ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
○ The participant would continue to be included in the study.
○ Not applicable – informed consent will not be sought from any participants in this research.
○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

☐ Access to medical records by those outside the direct healthcare team
☐ Electronic transfer by magnetic or optical media, email or computer networks

- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☐ Use of audio/visual recording devices
- ☑ Storage of personal data on any of the following:
  - ☑ Manual files including X-rays
  - ☑ NHS computers
  - ☐ Home or other personal computers
  - ☐ University computers
  - ☐ Private company computers
  - ☐ Laptop computers

Further details:
The required paper data will be securely kept separately from participant's notes/files, locked in a designated file drawer in the relevant base/premises. Any electronic data will be anonymised, collated and entered onto a database within the appropriate premises to ensure the security of the patient's files. No identifiable information will leave the premises. The anonymised electronic data will be stored on an encrypted device to further ensure security. This data will be kept by the NWCCP until the elapsing of a specified time period. The collated data will be completely anonymised and stored securely in accordance with the Data Protection Act.

Any data collected or recorded through the means of a potential semi-structured interviews shall be stored in a similar manner, with any recorded data being erased immediately after its transcription. Any data collected in this manner shall be anonymised to prevent personal identification and ensure confidentiality. Devices such as Dictaphones, and all electronic/related data encrypted on a SafeStick, shall be securely locked in a box, and will be brought to and from base (if required) in a locked box/cabinet.

A37. Please describe the physical security arrangements for storage of personal data during the study?

See above A36

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

See above A36

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

No other individuals or parties outside the direct care team will have access to participants' personal data.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

In accordance with the Data Protection Act, data will be anonymised and stored on an encrypted device before leaving any BCUHB premises. The anonymised data will be analysed by the Principal Investigator once data collection has been completed. As data will be fully anonymised, the principle investigator will analyse the data using their personal computer and the encryption device.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Mr	Neil	Clapton
Post	Trainee Clinical Psychologist		
Qualifications	BSc (Hons) Psychology		
Work Address	North Wales Clinical Psychology Programme		
	Brigantia Building, Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2DG		
Work Email	psp2d9@bangor.ac.uk		
Work Telephone	07825542644		
Fax			

A43. How long will personal data be stored or accessed after the study has ended?

- (●) Less than 3 months
- ( ) 3 – 6 months
- ( ) 6 – 12 months
- ( ) 12 months – 3 years
- ( ) Over 3 years

A44. For how long will you store research data generated by the study?

Years: 5
Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be stored, who will have access and the arrangements to ensure security.*

Research data on the encryption device will be securely stored in the North Wales Clinical Psychology Programme (NWCPP) for up to 5 years. This is due to NWCPP data availability policy for the Doctorate of Clinical Psychology.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

( ) Yes (●) No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

( ) Yes (●) No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

( ) Yes (●) No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

◉ Yes ○ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?

◉ Yes ○ No

It should be made clear in the participant's information sheet if the GP/health professional will be informed.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that "every clinical trial must be registered on a publicly accessible database before recruitment of the first subject"; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.

○ Yes ◉ No

Please give details, or justify if not registering the research.
This is not the type of research suitable for registration on a public database. However, all research conducted at Bangor University forms part of the university's repository, which is publicly accessible.

Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- ☑ Peer reviewed scientific journals
- ☑ Internal report
- ☑ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

No identifiable personal data will be used in the study.

A53. Will you inform participants of the results?

◉ Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Feedback of the results will be offered to all parties involved in the study. Participants will be offered the choice of which method (one-to-one session, letter, telephone call) they would like to receive the feedback, if any. Preference shall be sought at the stage of initial consent.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- ☐ Independent external review
- ☐ Review within a company
- ☐ Review within a multi−centre research group
- ☑ Review within the Chief Investigator's institution or host organisation
- ☑ Review within the research team
- ☑ Review by educational supervisor
- ☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The current research proposals has been submitted to the NWCPP research department to be assessed and approved. The principle investigator has received approval from the NWCPP research department.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? *Tick as appropriate:*

- ☐ Review by independent statistician commissioned by funder or sponsor
- ☐ Other review by independent statistician
- ☐ Review by company statistician
- ☑ Review by a statistician within the Chief Investigator's institution
- ☑ Review by a statistician within the research team or multi−centre group
- ☑ Review by educational supervisor
- ☐ Other review by individual with relevant statistical expertise
- ☐ No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title	Forename/Initials	Surname
	Dr	Gemma	Griffith
Department	North Wales Clinical Psychology Programme (NWCPP) Research Department		
Institution	Bangor University		
Work Address	North Wales Clinical Psychology Programme (NWCPP) Bangor University Bangor		
Post Code	LL57 2DG		
Telephone	01248388365		

Fax 01248383718
Mobile
E-mail g.m.griffith@bangor.ac.uk

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

The primary outcome measure will be changes in overall psychological distress and well-being, as measured by the PTOS-ID II (referring to relevant clinical cut-offs).

A58. What are the secondary outcome measures? *(if any)*

The secondary outcome measures will be changes in overall level self-compassion, social comparison, and shame, as measured by the Self-Compassion Scale-Short Form and Social Comparison Scale.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 20
Total international sample size (including UK):
Total in European Economic Area:

Further details:
A minimum of two groups (no more than three) shall be run to ensure there are adequate numbers of participants and data to conduct a meaningful analysis.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The sample size for the research has been based on the running of related previous groups to obtain adequate and meaningful data for analysis (Idusohan-Moizer et al, 2013).

A61. Will participants be allocated to groups at random?

○ Yes ◉ No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The statistical software package SPSS will be used to analyse the collated data. Data analysis is likely to include a number of within group comparisons for scores obtained at various time points (e.g. pre-group and post-group), utilising t-tests to compare mean scores (where data is normally distributed, or non-parametric equivalent where this is not the case), and appropriate effect size analysis.

Any semi-structured interviews will be based on previous interview schedules developed to examine the feasibility and acceptability of CFT groups (Heriot-Maitland et al, 2014), and are likely to be analysed utilising deductive thematic analysis, in accordance with suggestions by Braun & Clarke (2006).

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Professor	Robert	Jones
Post	Programme Director		
Qualifications	DClinPsy, BSc (Hons) Psychology		
Employer	Bangor University		
Work Address	North Wales Clinical Psychology Programme School of Psychology, Bangor University Bangor, Gwynedd		
Post Code	LL57 2AS		
Telephone	01248 382627		
Fax			
Mobile			
Work Email	r.s.jones@bangor.ac.uk		

	Title	Forename/Initials	Surname
	Dr	Jonathan	Williams
Post	Senior Clinical Psychologist		
Qualifications	DClinPsy, BSc (Hons) Psychology		
Employer	Betsi Cadwaladr University Health Board		
Work Address	Denbighshire Complex Disabilities Team B7, Trem Y Dyffryn, Colomendy Industrial Estate Denbigh, Denbighsire		
Post Code	LL16 5TX		
Telephone	01824 712750		
Fax			
Mobile			
Work Email	jonathan.williams@wales.nhs.uk		

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ○ NHS or HSC care organisation
- ◉ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- ○ Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation: School of Psychology, Bangor University
Given name: Hefin

Family name	Francis
Address	School of Psychology, Adeilad Building
Town/city	Bangor
Post code	LL57 2AS
Country	UNITED KINGDOM
Telephone	01248388339
Fax	01248382599
E-mail	h.francis@bangor.ac.uk

Is the sponsor based outside the UK?
○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☑ No application for external funding will be made

What type of research project is this?

○ Standalone project
○ Project that is part of a programme grant
○ Project that is part of a Centre grant
◉ Project that is part of a fellowship/ personal award/ research training award
○ Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes ◉ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Dr	Rossela	Roberts
Organisation	Clinical Governance Officer, BCUHB		

Address	Research and Development Office Clinical School Ysbyty Gwynedd
Post Code	LL57 2PW
Work Email	rossela.roberts@wales.nhs.uk
Telephone	01248383877
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 02/03/2015
Planned end date: 06/06/2016
Total duration:
Years: 1 Months: 3 Days: 5

A71-1. Is this study?

- (•) Single centre
- ( ) Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

- [ ] England
- [ ] Scotland
- [x] Wales
- [ ] Northern Ireland
- [ ] Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?
( ) Yes (•) No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

- [ ] NHS organisations in England
- [x] NHS organisations in Wales 1
- [ ] NHS organisations in Scotland
- [ ] HSC organisations in Northern Ireland
- [ ] GP practices in England
- [ ] GP practices in Wales
- [ ] GP practices in Scotland
- [ ] GP practices in Northern Ireland
- [ ] Social care organisations
- [ ] Phase 1 trial units
- [ ] Prison establishments

☐ Probation areas
☐ Independent hospitals
☐ Educational establishments
☐ Independent research units
☐ Other (give details)

Total UK sites in study: 1

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

◯ Yes ◉ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

Monitoring of the research will be completed by the NWCPP. This will consist of frequent research progress reports to the NWCPP research department. The principal investigator's research supervisor (Dr Jonathan Williams) will also monitor the study's progress through regular meetings.

A75-1. What arrangements will be made to review interim safety and efficacy data from the trial? Will a formal data monitoring committee or equivalent body be convened?

No formal procedures or bodies/committees involved; frequent monitoring by academic supervisor will be utilised to review safety and efficacy.

If a formal DMC is to be convened, please forward details of the membership and standard operating procedures to the Research Ethics Committee when available. The REC should also be notified of DMC recommendations and receive summary reports of interim analyses.

A75-2. What are the criteria for electively stopping the trial or other research prematurely?

Lack of attendance and/or significant drop-out from the study.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☑ Other insurance or indemnity arrangements will apply (give details below)

The study will be insured by Bangor University (indemnity certificate enclosed).

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☑ Other insurance or indemnity arrangements will apply (give details below)

See A76-1

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

See A76-1

Please enclose a copy of relevant documents.

A77. Has the sponsor(s) made arrangements for payment of compensation in the event of harm to the research participants where no legal liability arises?

○ Yes ◉ No

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes ○ No ◉ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	Betsi Cadwaldr University Health Board	Title	Dr
Department name	Denbighshire Complex Disabilities Team	First name/ Initials	Jonathan
Street address	B7, Trem Y Dyffryn, Colomendy Industrial Estate	Surname	Williams
Town/city	Denbigh		
Post Code	LL16 5TX		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. I understand that the main REC or its operational managers may share information in this application or supporting documentation with the Medicines and Healthcare products Regulatory Agency (MHRA) where it is relevant to the Agency's statutory responsibilities.

12. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further

information. We would be grateful if you would indicate one of the contact points below.

- (•) Chief Investigator
- ( ) Sponsor
- ( ) Study co-ordinator
- ( ) Student
- ( ) Other – please give details
- ( ) None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Mr Neil Clapton on 11/06/2015 20:14.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	BCUHB
Email:	psp2d9@bangor.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Mr Hefin Francis on 15/06/2015 09:27.

Job Title/Post:	School Manager for Psychology
Organisation:	Bangor University
Email:	h.francis@hotmail.com

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Professor Robert Jones on 11/06/2015 20:33.

Job Title/Post:	Programme Director
Organisation:	NWCPP
Email:	r.s.jones@bangor.ac.uk

Site Specific Information Form

NHS SSI IRAS Version 4.0.0

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Adapted group-based CFT for people with Intellectual Disabilities V2

1. Is your project research?

◉ Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product
○ Clinical investigation or other study of a medical device
○ Combined trial of an investigational medicinal product and an investigational medical device
◉ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
○ Basic science study involving procedures with human participants
○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
○ Study involving qualitative methods only
○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
○ Study limited to working with data (specific project only)
○ Research tissue bank
○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Will the study involve the use of any medical device without a CE Mark, or a CE marked device which has been modified or will be used outside its intended purposes?

○ Yes ◉ No

2b. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	○ Yes	◉ No
b) Will you be taking new human tissue samples (or other human biological samples)?	○ Yes	◉ No
c) Will you be using existing human tissue samples (or other human biological samples)?	○ Yes	◉ No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

☐ England
☐ Scotland
☑ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

○ England
○ Scotland
◉ Wales
○ Northern Ireland
○ This study does not involve the NHS

4. Which review bodies are you applying to?

☑ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☑ Research Ethics Committee
☐ Confidentiality Advisory Group (CAG)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

(●) Yes ( ) No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

( ) Yes (●) No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

( ) Yes (●) No

Site-Specific Information Form (NHS sites)

Is the site hosting this research a NHS site or a non-NHS site? *NHS sites include Health and Social Care organisations in Northern Ireland. The sites hosting the research are the sites in which or through which research procedures are conducted. For NHS sites, this includes sites where NHS staff are participants.*

- (●) NHS site
- ( ) Non-NHS site

This question must be completed before proceeding. The filter will customise the form, disabling questions which are not relevant to this application.

One Site-Specific Information Form should be completed for each research site and submitted to the relevant R&D office with the documents in the checklist. See guidance notes.

The data in this box is populated from Part A:

Title of research:
Growing Kind Minds: A feasibility study and preliminary trial of adapted group-based Compassion Focused Therapy for people with Intellectual Disabilities (CFT-ID)

Short title: Adapted group-based CFT for people with Intellectual Disabilities V2

Chief Investigator:	Title	Forename/Initials	Surname
	Mr	Neil	Clapton

Name of NHS Research Ethics Committee to which application for ethical review is being made:
Wales REC 5

Project reference number from above REC: 15/WA/0226

1-1. Give the name of the NHS organisation responsible for this research site

Betsi Cadwaladr University Health Board

1-3. In which country is the research site located?

- ( ) England
- (●) Wales
- ( ) Scotland
- ( ) Northern Ireland

1-4. Is the research site a GP practice or other Primary Care Organisation?

( ) Yes (●) No

2. Who is the Principal Investigator or Local Collaborator for this research at this site?

Select the appropriate title: (•) Principal Investigator
( ) Local Collaborator

	Title	Forename/Initials	Surname
	Mr	Neil	Clapton
Post	Trainee Clinical Psychologist		
Qualifications	BSc (Hons) Psychology		
Organisation	NHS		
Work Address	North Wales Clinical Psychology Programme Brigantia Building, Bangor University Bangor, Gwynedd		
PostCode	LL57 2DG		
Work E-mail	psp2d9@bangor.ac.uk		
Work Telephone	07825542644		
Mobile	07825542644		
Fax			

a) Approximately how much time will this person allocate to conducting this research? *Please provide your response in terms of Whole Time Equivalents (WTE).*
0.3 WTE

b) Does this person hold a current substantive employment contract, Honorary Clinical Contract or Honorary Research Contract with the NHS organisation or accepted by the NHS organisation? (•) Yes ( ) No

A copy of a current CV for the Principal Investigator (maximum 2 pages of A4) must be submitted with this form.

3. Please give details of all locations, departments, groups or units at which or through which research procedures will be conducted at this site and describe the activity that will take place.

Please list all locations/departments etc where research procedures will be conducted within the NHS organisation, describing the involvement in a few words. Where access to specific facilities will be required these should also be listed for each location.

Name the main location/department first. Give details of any research procedures to be carried out off site, for example in participants' homes.

	Location	Activity/facilities
1	Denbighshire Complex Disabilities Team, B7, Trem Y Dyffryn, Colomendy Industrial Estate Denbigh, Denbighsire, LL16 5TX	Co-ordination of all research activities
2	TBA Location(s) within North Wales Learning Disability Services	Running of group
3	TBA North Wales Learning Disability Teams	Assessments: capacity to consent, pre and post-group

5. Please give details of all other members of the research team at this site.

1

	Title	Forename/Initials	Surname
	Dr	Jonathan	Williams
Work E-mail	jonathan.williams@wales.nhs.uk		

Employing organisation	Betsi Cadwaladr University Health Board
Post	Senior Clinical Psychologist
Qualifications	DClinsPsy, BSc
Role in research team:	researcher

a) Approximately how much time (approximately) will this person allocate to conducting this research? *Please provide your response in terms of Whole Time Equivalents (WTE).*
0.1 WTE

b) Does this person hold a current substantive employment contract, Honorary Clinical Contract or Honorary Research Contract with the NHS organisation or accepted by the NHS organisation? ◉ Yes ○ No

A copy of a current CV for the research team member (maximum 2 pages of A4) must be submitted to the R&D office.

6. Does the Principal Investigator or any other member of the site research team have any direct personal involvement (e.g. financial, share-holding, personal relationship etc) in the organisation sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

7. What is the proposed local start and end date for the research at this site?

Start date:	01/06/2015
End date:	06/06/2016
Duration (Months):	12

8-1. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *(These include seeking consent, interviews, non-clinical observations and use of questionnaires.)*

Columns 1-4 have been completed with information from A18 as below:

1. *Total number of interventions/procedures to be received by each participant as part of the research protocol.*
2. *If this intervention would have been routinely given to participants as part of their care, how many of the total would have been routine?*
3. *Average time taken per intervention (minutes, hours or days)*
4. *Details of who will conduct the procedure, and where it will take place*

Please complete Column 5 with details of the names of individuals or names of staff groups who will conduct the procedure at this site.

Intervention or procedure	1	2	3	4	5
Participant approached regarding potential involvement in group & study	1	0	15 minutes	Initially approached by lead clinician/healthcare professional as regards potential interest.	
Consent - assess capacity & obtain informed consent	1	0	15 minutes	Principal investigator to explain group/study and provide with relevant information, obtain informed consent, preferably in presence of carer/lead healthcare professional to corroborate capacity.	

Pre-group Assessment	1	0	45 minutes	Assessment undertaken by Principal investigator. Will involve administration and completion of all relevant psychometric measures, including: PTOS ID-II, Self-Compassion Scale, Social Comparison Scale. Assessment process should take no longer than 1 hour, and will be completed at a convenient time, date and location for the participant.
Post-group Assessment	1	0	1 hour	Assessment undertaken by Principal investigator. Will involve administration and completion of all relevant psychometric measures, including: PTOS ID-II, Self-Compassion Scale, Social Comparison Scale. Assessment process should take no longer than 1 hour, and will be completed at a convenient time, date and location for the participant.
Evaluation session	1	0	1 hour	Focus group/semi-structured interview session to be conducted by a Trainee Clinical Psychologist within the Learning Disabilities Service.

8-2. Will any aspects of the research at this site be conducted in a different way to that described in Part A or the protocol?

○ Yes ◉ No

If Yes, please note any relevant changes to the information in the above table.

Are there any changes other than those noted in the table?

9-1. Give details of any clinical intervention(s) or procedure(s) to be received by participants as part of the research protocol. *(These include uses of medicinal products or devices, other medical treatments or assessments, mental health interventions, imaging investigations and taking samples of human biological material. Include procedures which might be received as routine clinical care outside of the research.)*

Columns 1-4 have been completed with information from A19 as below:

1. *Total number of interventions to be received by each participant as part of the research protocol*
2. *If this intervention would have been routinely given to participants as part of their care, how many of the total would have been routine?*
3. *Average time taken per intervention (minutes, hours or days)*
4. *Details of who will conduct the procedure, and where it will take place*

Please complete Column 5 with details of the names of individuals or names of staff groups who will conduct the procedure at this site.

Intervention or procedure	1	2	3	4	5
CFT group - 6 sessions	6	0	6-9 hours	Principal Investigator and supervisor to facilitate running of group sessions. Group shall be run at a	

	location that is easily and readily accessible for the majority of participants.

9-2. Will any aspects of the research at this site be conducted in a different way to that described in Part A or the protocol?

○ Yes ◉ No

If Yes, please note any relevant changes to the information in the above table.

Are there any changes other than those noted in the table?

10. How many research participants/samples is it expected will be recruited/obtained from this site?

The study plans to recruit approximately 20 people.

11. Give details of how potential participants will be identified locally and who will be making the first approach to them to take part in the study.

Participants will be recruited from those individuals open to the NHS Community Learning Disabilities Teams in North Wales. The nature and aims of the study will be discussed within appropriate multidisciplinary team meetings,, and team members will be encouraged to identify and refer potentially suitable candidates that meet the inclusion criteria. All identification will therefore be made through members of the direct care team(s). Potential participants will be primarily approached by their lead healthcare professional or key worker to ascertain their interest in taking part in the research.

12. Who will be responsible for obtaining informed consent at this site? What expertise and training do these persons have in obtaining consent for research purposes?

Name	Expertise/training
Neil Clapton	Previous experience of working in Learning Disabilities Services, which involved being familiar with principles and processes of establishing capacity to consent and obtaining such informed consent (for assessments and formal therapy). Doctoral training also extensively covers capacity/consent, how to assess and how to obtain. Principal investigator has also developed rigorous capacity to consent protocol based on previous and current research/guidelines.

15-1. Is there an independent contact point where potential participants can seek general advice about taking part in research?

Yes - participants are encouraged and advised to talk about their participation with someone they trust (carer, key worker), who are impartial and not directly connected to the research. However, there is no other independent contact regarding general advice.

15-2. Is there a contact point where potential participants can seek further details about this specific research project?

Yes - participants will be able to contact the principal investigator for further information or questions about the research (information is at the end of the Participant Information form).

16. Are there any changes that should be made to the generic content of the information sheet to reflect site-specific issues in the conduct of the study? *A substantial amendment may need to be discussed with the Chief Investigator and*

submitted to the main REC.

No.

Please provide a copy on headed paper of the participant information sheet and consent form that will be used locally. Unless indicated above, this must be the same generic version submitted to/approved by the main REC for the study while including relevant local information about the site, investigator and contact points for participants (see guidance notes).

17. What local arrangements have been made for participants who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters etc.)*

All participant information sheets and consent forms shall be pre sented in an easy-read manner with appropriate visual supports. W here appropriate, steps will be taken for participants to indicat e their responses in a non-verbal manner (e.g. using visual supports). If there is any doubt about a participant's ability to understand the information or communicate that they have fully understood the information presented, capacity to consent shall not be assumed and they will not be included in the study.

Given that the population is located in North Wales, every a ttempt will be made to accommodate individuals who are Welsh First Language speakers. This will include the availability of any prior consent forms and related material in Welsh (and a Welsh speaker to convey information), and (if possible) the translation of group materials into Welsh.

18. What local arrangements will be made to inform the GP or other health care professionals responsible for the care of the participants?

GPs and other relevant healthcare professional(s) will be informed of their client's participation in the research by letter.

19. What arrangements (e.g. facilities, staffing, psychosocial support, emergency procedures) will be in place at the site, where appropriate, to minimise the risks to participants and staff and deal with the consequences of any harm?

The study plans to provide a potential parallel one-off session for carers and involved healthcare professionals to understand the CFT model, processes and principal components, and how to assist individuals they care for/work with practice self-compassion in daily life (e.g. complete personal practice between groups).

Prior to starting the assessment process or attending the group, the principal investigator shall establish with the participant(s) an agreed way of communicating if they are distressed. Should this happen at any point, the principal investigator shall halt the assessment or group process and address the immediate distress, and subsequently ascertain whether the participant wishes to continue or not. If not, the participant shall be directed to further appropriate support. The principal investigator will contact the participant's lead clinician, with the participant's consent, to inform them about the participant's current situation. Support will be available (via consultation) for staff should they need any advice/support in addressing concerns or distress.

20. What are the arrangements for the supervision of the conduct of the research at this site? *Please give the name and contact details of any supervisor not already listed in the application.*

Weekly supervision between the principal investigator and supervisor (Dr Jonathan Williams) shall ensure the conducting of such research is effectively monitored and continuously evaluated. This will also be supported by as-and-when contact with the Research Team at Bangor University (for the North Wales Clinical Psychology Programme).

21. What external funding will be provided for the research at this site?

- ○ Funded by commercial sponsor
- ◉ Other funding
- ○ No external funding

Please give details of the funding:
Bangor University
This research is part of the DClinPsy programme and is conducted in the research sessions of the NWCPP (North Wales Clinical Psychology Programme). It will ahve no cost implications for BCUHB as it requires no resources. All research activities shall be run by the trainee/principal investigator and academci superviosr.

Type of funding	Details (including breakdown over years if appropriate)
(i) Block grant	
(ii) Per participant	
(iii) Other (give details)	

Which organisation will receive and manage this funding?

23. Authorisations required prior to R&D approval

The local research team are responsible for contacting the local NHS R&D office about the research project. Where the research project is proposed to be coordinated centrally and therefore there is no local research team, it is the responsibility of the central research team to instigate this contact with local R&D.

NHS R&D offices can offer advice and support on the set-up of a research project at their organisation, including information on local arrangements for support services relevant to the project. These support services may include clinical supervisors, line managers, service managers, support department managers, pharmacy, data protection officers or finance managers depending on the nature of the research.

Obtaining the necessary support service authorisations is not a pre-requisite to submission of an application for NHS research permission, but all appropriate authorisations must be in place before NHS research permission will be granted. Processes for obtaining authorisations will be subject to local arrangements, but the minimum expectation is that the local R&D office has been contacted to notify it of the proposed research project and to discuss the project's needs **prior** to submission of the application for NHS research permission via IRAS.

Failure to engage with local NHS R&D offices **prior** to submission may lead to unnecessary delays in the process of this application for NHS research permissions.

Declaration:

☑ **I confirm that the relevant NHS organisation R&D office has been contacted to discuss the needs of the project and local arrangements for support services. I understand that failure to engage with the local NHS R&D office before submission of this application may result in unnecessary delays in obtaining NHS research permission for this project.**

Please give the name and contact details for the NHS R&D office staff member you have discussed this application with:

Please note that for some sites the NHS R&D office contact may not be physically based at the site. For contact details refer to the guidance for this question.

	Title	Forename/Initials	Surname
	Mrs	Rossela	Roberts
Work E-mail	Rosella.Roberts@wales.nhs.uk		
Work Telephone	01248384877		

Declaration by Principal Investigator or Local Collaborator

1. The information in this form is accurate to the best of my knowledge and I take full responsibility for it.
2. I undertake to abide by the ethical principles underpinning the World Medical Association's Declaration of Helsinki and relevant good practice guidelines in the conduct of research.
3. If the research is approved by the main REC and NHS organisation, I undertake to adhere to the study protocol, the terms of the application of which the main REC has given a favourable opinion and the conditions requested by the NHS organisation, and to inform the NHS organisation within local timelines of any subsequent amendments to the protocol.

4. If the research is approved, I undertake to abide by the principles of the Research Governance Framework for Health and Social Care.

5. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to the conduct of research.

6. I undertake to disclose any conflicts of interest that may arise during the course of this research, and take responsibility for ensuring that all staff involved in the research are aware of their responsibilities to disclose conflicts of interest.

7. I understand and agree that study files, documents, research records and data may be subject to inspection by the NHS organisation, the sponsor or an independent body for monitoring, audit and inspection purposes.

8. I take responsibility for ensuring that staff involved in the research at this site hold appropriate contracts for the duration of the research, are familiar with the Research Governance Framework, the NHS organisation's Data Protection Policy and all other relevant policies and guidelines, and are appropriately trained and experienced.

9. I undertake to complete any progress and/or final reports as requested by the NHS organisation and understand that continuation of permission to conduct research within the NHS organisation is dependent on satisfactory completion of such reports.

10. I undertake to maintain a project file for this research in accordance with the NHS organisation's policy.

11. I take responsibility for ensuring that all serious adverse events are handled within the NHS organisation's policy for reporting and handling of adverse events.

12. I understand that information relating to this research, including the contact details on this application, will be held by the R&D office and may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

13. I understand that the information contained in this application, any supporting documentation and all correspondence with the R&D office and/or the REC system relating to the application will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

This section was signed electronically by Mr Neil Clapton on 11/06/2015 20:09.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	BCUHB
Email:	psp2d9@bangor.ac.uk

R&D Review Panel – Request for further information

Dear Mr Neil Clapton

Re: BCUHB R&D – request for information/clarification - response required

Study Title	**Adapted group based CFT for people with Intellectual Disabilities**
IRAS reference	184366

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel (IRP) on **09th July 2015**.

The IRP discussed the research governance issues arising under the following checks:

Protocol assessment

The Panel considered whether the objectives, design, methodology, statistical considerations (methods of data analysis) and the organisation of the study are appropriately described in the protocol. The panel noted that throughout the protocol documentation the words pilot, preliminary trial and feasibility were used.

Participant information / consent documents and process

The Panel considered the proposed consent process to ensure that any legal implications presented by the study are highlighted, and considered the accuracy of the information provided. The Panel noted how the R&D form states “direct quotes to be published” but the Info sheet does not give information around this.

Risks to NHS organisation assessed

The Panel noted that the Risk Assessment completed by the study had not been signed or dated.

The Panel considered the potential risks generated by the study, the consequences of those risks and the arrangements for mitigation. It was noted that the Risk Assessment Form has been completed by the researcher but an overall risk category has not been adequately assigned.

The Panel concluded that this is a LOW risk hosted study and there would be no requirement for site monitoring unless there are concerns identified from central monitoring that cannot be addressed by any other means; the audit plan will request the submission of progress reports; the study may be included in other audits.

Implications for internal departments assessed

The Panel discussed the additional work to support a study, ensuring that each department has assessed the impact of any additional procedures on their routine

work. The Panel asked for clarification as to who within the HB will be assisting with the identification of participants and for confirmation from the department stating they are happy for staff to take part.

Before confirming its final opinion the Panel asked for a complete response to the issues identified in the following governance checks:

Participant information / consent documents and process

The Panel would like clarification regarding "direct quotes to be published" and the need to reflect this within the participant Information Sheet as necessary.

Implications for internal departments assessed

The Panel asked for details as to who within BCUHB will be identifying participants. A signature should be obtained from the CoS (or equivalent) as confirmation they support the study and are happy for BCU staff to take part.

Authority to consider the further information and to confirm the Panel's final opinion has been delegated to the Chairman.

If you would like further information on any other points covered by this letter please do not hesitate to contact me directly. *A response should be returned to me within 14 days of this notification email.*

Yours sincerely

Debra Slater

Research Governance Officer

Betsi Cadwaladr University Health Board (BCUHB)

Ysbyty Gwynedd

Penrhos Garnedd

Bangor

LL57 2PW

Te. 01248 384877 / 01352 718382

Response to R&D request for further information

Date: 16/07/2015

Dear Debra,

Thank you for your email/letter. The following response(s) outline how the issues identified have been addressed:

(1) Partcipant Information / consent documents and process

In terms of clarity surrounding "direct quotes to be published", this relates to the collection and recording of information through a focus group utilising a semi-structured interview schedule. This process usually encompasses the recording of such a session, which is then anonymised, transcribed, analysis conducted (e.g. searching for themes), upon which quotes are sometimes utilised to reflect the common/over-arching themes identified by participants. Please refer to A36 and A62 of the IRAS form.

The PIS and Consent forms highlight that information shared in the focus group will be recorded (of which consent is sought). A sentence has been added to the PIS (see attached) to highlight that information shared in the focus group may be written up in published material, but that this will be completely anonymised.

(2) Implications for internal departments assessed

In terms of clarity around who within BCUHB will be identifying participants, these will be identified by colleagues within BCUHB Community Mental Health teams (please refer to A13 and A27-1 of the IRAS form). The inclusion/exclusion criteria and nature of the group will be explained to Mental Health colleagues in appropriate forums (e.g. team meetings), so they can begin to identify potentially suitable participants. Potential participants will then be approached by the relevant (primary) healthcare professional with information about the study (the Participant Information Sheet), of which they can then preliminarily express interest in taking part and agree to be seen by the principal investigator to ascertain capacity to consent, formally consent to participation, and subsequent pre-group assessment.

A signature has been requested from the CoS equivalent (Mike Sinnott) as confirmation they support the study and are happy for BCU staff to take part.

Kindest Regards,

Neil Clapton

R&D Review Panel – R&D Approval

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D - Canolog
R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: rossela.roberts@wales.nhs.uk
debra.slater@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

Mr. Neil Clapton
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
Brigantia Building, Bangor University
Bangor,
Gwynedd
LL57 2DG
Psp2d9@bangor.ac.uk

20th July 2015

Dear Mr Neil Clapton

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title	Growing Kind Minds: A feasibility study and preliminary trial of adapted group-based Compassion Focused Therapy for people with Intellectual Disabilities (CFT-ID)
IRAS reference	184366
REC reference	15/WA/0226

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

Thank you for responding to the Panel's request for further information. The R&D office considered the response on behalf of the Panel and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board (BCUHB) sites as described in the application.

The documents reviewed and approved are listed below:

Document:	Version	Date
R&D Form	4.0.0	11/06/2015
SSI Form	4.0.0	11/06/2015
Protocol	V1	03/06/2015
LSRP Proposal	V1	15/0/2014
Managing distress and incidental disclosure protocol	V1	03/06/2015
Participant Information Sheet	V3	03/07/2015
Consent Form	V2	03/06/2015
GP/HC Prof assessment distress letter (raising concerns)	V1	13/04/2015
GP/HC Prof notification letter	V1	13/04/2015
Guidelines for functional assessment of capacity	V2	03/06/2015
The Social Comparison Scale (LD Adapted)	No version	No date
Self Compassion Scale (SCS-SF ID)	V1	No date
Psychological Therapies Outcome Scale (PTOS-ID II)	No version	No date
Feasibility & Acceptability Measure (CFT-ID)	V1	03/06/2015
Interview schedule – service users	V1	13/04/2015
Summary CV: Clapton	V1	13/04/2015
Summary CV: Williams		Undated

Evidence of Insurance (QBE)		Expires 31/07/2015
Risk Assessment		15/05/2015
REC favourable opinion letter		22/06/2015

All research conducted at the Betsi Cadwaladr University Health Board (BCUHB) sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please go to: http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979. Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at:http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571 and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:
http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.
Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact debra.slater@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Panel, may I take this opportunity to wish you every success with your research.

Yours sincerely,

Rossela Roberts

Dr. Rossela Roberts, MICR, CSci
Clinical Governance Officer (R&D/Ethics)

Copy to:

Sponsor:	Mr Hefin Francis School of Psychology, Brigantia Building Bangor University Bangor LL57 2AS	h.francis@bangor.ac.uk
Academic Supervisor:	Professor Robert Jones Programme Director, North Wales Clinical Psychology Programme School of Psychology, Bangor University Bangor LL57 2AS	r.s.jones@bangor.ac.uk

FORMS, MEASURES, AND MATERIALS

Participant Information Sheet – Growing Kind Minds group and study

Information about the Research

About me

This is Neil Clapton. He is a trainee Clinical Psychologist at Bangor University. Clinical Psychologists are trained to help people who have difficulties in their daily life.

He is doing some research and would like to ask for your help.

What is research?

Research is finding out about things.

Neil's research is looking at what happens to people when they are helped to be kinder towards themselves.

What is the research about?

Neil is going to be running some groups. These groups help people cope with how they feel, by learning to be kinder to

themselves. Neil would like to find out if this might help people feel better about themselves.

What happens in the group?

The group will involve practicing lots of different ways of being kind, caring and helpful to yourself, and learning how this can be helpful and useful in life.

Some of things you will practice in the group include:

- learning to breathe in a way that calms and relaxes you, and helps you think more clearly
- noticing and accepting what happens in your mind and body
- how to deal with difficult feelings like when you feel angry, worried, scared, upset, sad, no good
- talking to yourself in a kind and friendly voice, and how this can help calm you, feel stronger and feel happier.

How many sessions would I have to attend?

The group is six sessions long, takes place once a week, and will last for about an hour to an hour-and-a-half.

Where and When will the group take place?

The group will take place in …*(insert location here)*…….

at

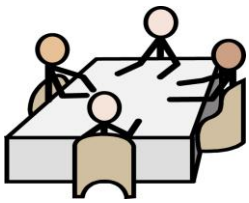
…(insert time here)…….

Why have I been asked to take part?

You have been asked to take part because you live in North Wales, you have a Learning Disability, and sometimes feel anxious, stressed, or low in mood.

What will happen?

1. If you want to take part, then please circle the ‘yes’ at the end of this information sheet. If you can, please sign your name at the bottom and give it back to your key worker. They will pass it on to Neil. You can keep a copy for yourself too.



2. If you say ‘yes’, Neil will meet with you to ask you some more questions and help you complete some forms.

   The first form is called a **Consent Form.** This form says that you understand what the group and study is about, and you want to take part.

   The other forms ask you about how you feel. We will also ask you these questions when the group is finished. This will help to see if the group is helpful or not.

   You can bring along someone you trust with you to talk to Neil, and to the group, if you want (e.g. your carer or key worker).

3. All the information you give will be kept private. No-one except Neil and the research team will know who you are.

4. When you have finished taking part in the group, you will have a chance to tell someone what you thought was good/bad about the group, and what was helpful/unhelpful. This is called a **focus group.** You will only be asked to do this just once. This will be done by one of Neil's colleagues, so that you are free to say whatever you want about the group. This will be recorded on a tape recorder. It is up to you whether or not you want to take part in the focus group.

   If you want, Neil will also let you know about the results of the group (e.g. did it help people feel better about themselves?).

What happens if I get really upset when answering questions or in the group?

If you become really upset when Neil asks you some questions about how you feel, he will try and help you feel less upset. You would also be able to get in touch with somebody you know from the learning disabilities team to help you with your problems. If it's OK, Neil might want to tell and write to your GP to let them know. Neil will ask you if this is OK when you meet with him. The same will happen if you become really upset when you come to the group.

What will happen if I tell you certain things about me?

Whatever you say will not be shared with anybody outside our research team. But, if you tell us something that makes us worried about you or other people (such as abuse), then the research team may need to talk about this with other people, such as the police or social services, to make sure that you are safe.

Do I have to take part?

- No. If you do not want to take part in the group, just say no.
- If you say yes, but then you change your mind, that is OK too.
- This will not affect the way you are treated now or in the future.

Would you like to take part in the research?

It is up to you to decide if you would like to take part. You can have some time to think about it and talk to someone you know about it.

YES

NO

Then sign/initial your name here:……..... and the date……

What if I have questions about the study?

If you have any questions you can phone or ask someone to phone Neil on xxxxxxxxxx. Or you can email Neil – his email address is psp2d9@bangor.ac.uk.

Complaints

If you have any complaints about this research, please contact:

Hefin Francis (school manager)

The School of Psychology,

Bangor University

Pen yr Allt Road

Bangor, Gwynedd

LL57 2AS.

Phone number: 01248 388339

Formal assessment of capacity to provide informed consent

Protocol for Assessing Capacity (Screening)

This protocol is based on procedures followed by Arscott, Dagnan, and Kroese (1998), and recommendations made by Bernal (2006), Cameron and Murphy (2006), McDonald and Kidney (2012), and Fisher et al (2006).

Read Information sheet once to/along with the potential participant, then say:

> "To take part in this research I need to be sure you understand what I am asking you to do. If it is ok, I will just ask you some questions about what we have just read'.

Questions

1. Read the following part of the Information sheet: "We are doing research about what happens to people when they are helped to be kinder towards themselves. These groups help people cope with how they feel, and be kinder to themselves. We would like to find out if this group might help people feel better by helping them to be more kind, caring, and helpful to themselves."

Ask the participant: "**What is the research and group about?**"

Score 2 for a clear and accurate answer such as "To find out if people feel better when they are helped to be kinder to themselves."

Score 1 if the person gives an answer similar to but less clear than above response

Score 0 if the answer is irrelevant or too vague (e.g. "See me").

2. Read the following part of the information sheet: "You have been asked to take part because you live in North Wales and have been assessed as having a Learning Disability, and because we have been told that you often feel very anxious/worried, stressed, and/or depressed."

Ask the participant: "**Why have you been asked to take part in the group/research?**"

Score 2 for a clear and accurate answer such as "Because I have a Learning Disability" and/or "I often get very anxious/worried, stressed, depressed."

Score 1 if the person gives an answer similar to but less clear than above response

Score 0 if the answer is irrelevant or too vague (e.g. "See me").

3. Read the following part of the Information sheet: "If you want to take part, then please fill in the consent form, which is in this information pack. This form says that you understand what the group and study is about, and you want to be part of the research.

"If you have signed the consent form, Neil will then want to ask you some more questions about how you feel, and help you complete some forms."

Ask the participant: "**What will happen next if you want to take part?**"

Score 2 for answer similar to "Sign a form to say yes, and then Neil will want to ask me some more questions, and help me complete some forms."

Score 1 if the person gives an answer similar to but less clear than above response.

Score 0 for incorrect answer or an answer that is too vague.

4. Ask the participant "**Are you happy to take part in the group/research?**"

Answers Yes or No.

For consent to be given the participant needs to answer Yes to question 4

5. Read the following part of the Information sheet: "If you do not want to take part in the group/research, just say no. If you say yes, but then you change your mind, that is OK too."

Ask the participant: "**What will you do if you change your mind?**"

Score 2 for a clear and accurate answer such as "tell you I don't want to do it anymore."

Score 1 if the person gives an answer similar to but less clear than above response

Score 0 if answer is irrelevant or too vague.

Overall scoring

		2	**1**	**0**
Question 1	What is the group/research about?			
Question 2	Why have you been asked to take part?			
Question 3	What will happen next if you want to take part?			
Question 4	Are you happy to take part in the group/research?			
Question 5	What will you do if you change your mind?			

If the participant scores 0 to any of the questions under items 1, 2, 3 or 5, then the participant is assessed as not having the capacity to consent in this specific context.

If the participant scores 2 in every question under items 1,2, 3 and 5 and answers "Yes" to question 4, then the participant is assessed as having the capacity to consent and s/he is indicating their wish to participate. If the participant scores 2 in every question under items 1,2, 3 and 5 but answers "No" in question 4, the participant is assessed as having the capacity to consent and is indicating their refusal to participate.

If an individual scores 1 on **all** questions it would indicate that their responses are not very clear indicating that perhaps they are not adequately understanding the information. In this situation, you will need to discuss the individual's potential involvement with their carer or a member of staff who knows them well. Use your judgment to decide whether the individual has provided a sufficiently coherent understanding of the questions in the context of their level of intellectual disability, memory ability, and potential for suggestibility and acquiescence.

Particular attention should be given to the following other potential indicators (positive and doubtful) of consent (Cameron & Murphy, 2006):

POSITIVE INDICATORS	Yes		No	
	Assessor	Carer	Assessor	Carer
High level of engagement (e.g. eye contact, body language)				
Relevant elaboration (e.g. verbal comments indicating willing to take part)				
Positive non-verbal responses (e.g. nodding)				

DOUBTFUL INDICATORS	Yes		No	
	Assessor	Carer	Assessor	Carer
Low level of engagement (e.g. lack of eye contact, indifference)				
Concern that responses were overly acquiescent (e.g. agreeing without clear understanding)				
Ambivalent non-verbal responses (e.g. negative facial expression)				

Participants' responses and the above indicators should be discussed and corroborated with carers (if they are present) to check for agreement.

References

Arscott, K., Dagnan, D., & Kroese, B. S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *11*(1), 77-83.

Bernal, J. (2006). Consent and people with intellectual disabilities. *Understanding Intellectual Disability & Health.* http://www.intellectualdisability.info/how-to../consent-and-people-with-intellectual-disabilities-the-basics

Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, *35* (2), 113-120.

Fisher, C. B., Cea, C. D., Davidson, P. W., & Fried, A. L. (2006). Capacity of persons with mental retardation to consent to participate in randomized clinical trials. *The American Journal of Psychiatry*, *163* (10), 1813-1820.

McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, *9* (1), 27-39.

Participant Consent Form

Consent form – Growing Kind Minds group and study

If you would like to take part in the research, you need to do two things:

1) Answer the questions below (1-8) by putting a circle round the answer, and writing the initials of your name next to your answer

2) Sign and date the form (on the next page)

Questions

1. I have been given information about the group and the study

 YES .....  NO .....

2. I understand what the group and study is about

 YES .....  NO .....

3. I have been able to ask questions if I wanted

 YES .....  NO .....

4. I know that I can stop taking part at any time

 YES .....  NO .....

5. **I agree to take part in the study**

 YES .....  NO .....

6. I am happy for my doctor (GP) to be told that I am taking part

 YES .....  NO .....

7. I am happy for my doctor (GP) to be informed if I have any problems

 YES .....  NO .....

8. I understand that if I tell the therapist something that made them worry about me or somebody else, they would need to tell somebody

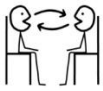
 YES .....  NO .....

I would like to be told about the results of the group

 YES .....  NO .....

I would like to be told the results by (please tick which one you would most like):

 ☐ Letter

 ☐ Meeting (face-to-face)

 ☐ E-mail

 ☐ Telephone

<u>FOCUS GROUP</u>

I would be happy to attend a focus group

 YES.....  NO .....

I am happy for my answers to be recorded on tape

 YES……  NO ……

PARTICIPANT

Name…… Date of Birth……

Signed…… Date…….

RESEARCHER

Name…….

Signed…… Date…….

GP/HC Professional Notification Letter

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU

NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

Ref:

Llyth-el/E-mail: psp2d9@bangor.ac.uk

Llinell Uniongyrchol/Direct line:

Date here 2015

Address Here

Dear (GP/Healthcare Professional),

I am writing to inform you that Xxxxxxx has consented to take part in a research project that I am carrying out as part of my doctoral research.

As part of the research, this will involve Xxxx attending a six-session Compassion Focused Therapy group. The group shall be running from (*insert dates here*) at (*insert location here*). The purpose of this research is to see if adapting this therapeutic approach for individuals with a Learning Disability in a group format is feasible, acceptable and efficacious. Additionally, we are attempting to initially explore whether helping individuals with Learning Disabilities and concurrent mental health issues be more compassionate to themselves reduces their overall level of psychological distress and improves well-being.

Capacity to and informed consent has been established and gained. It has been communicated and established that participation is entirely voluntary. He/she has been made aware that they can withdraw at anytime without any adverse consequences, and he/she does not have to give a reason.

If you have any further queries, please do not hesitate to contact me.

Yours sincerely

Neil Clapton

Trainee Clinical Psychologist

GP/HC Professional Undue Distress Letter

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU

NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

Ref:

Llyth-el/E-mail: psp2d9@bangor.ac.uk

Llinell Uniongyrchol/Direct line:

Date here 2015

Address Here

Dear (GP/Healthcare Professional),

Re: Xxxxxxxx Xxxxxxxx (*insert participant's details here*)

I am writing to you, with the consent of the above, to inform you of their current circumstances and concerns regarding their emotional well-being, having attended an assessment session with myself on XX/XX/XX. This was in preparation to attend a six-session Compassion Focused Therapy group that we are carrying out as part of my doctoral research.

During the assessment session, Xxxxxx became sufficiently distressed as to warrant cessation of the assessment. Whilst every attempt was made to ensure that Xxxxx's distress was appropriately addressed and resolved, it was agreed that (and they are aware of) we would contact you to inform you of this. I kindly ask that you further investigate and monitor Xxxxxxx's current level of distress and well-being, and take appropriate steps to address any unresolved distress/issues with them.

In the interests of Xxxxxxx's current well-being, they will no longer be required to complete the formal assessment process or take part in the aforementioned group and research.

If you have any further queries, please do not hesitate to contact me.

Yours sincerely

Neil Clapton

Trainee Clinical Psychologist

Protocol for managing undue distress and incidental disclosures

PROCESS AND PROTOCOL FOR MANAGING

UNANTICIPATED/UNDUE DISTRESS AND INCIDENTAL DISCLOSURES

The following document outlines processes, procedures and protocols to manage distress and incidental disclosures of harm/abuse for individuals with an Intellectual Disability that may occur in either the assessment or intervention phase of the outlined study.

This is in accordance with standard practice outlined in Betsi Cadwaladr University Health Board's Policy and Procedures for the Protection of Vulnerable Adults (POVA). All information in this protocol is taken and/or adapted from this specific document, and guidance/recommendations from the National Disability Authority's 'Ethical Guidance for research with People with Disabilities' (2009).

PROCESS(ES) FOR MANAGING INCIDENTAL DISCLOSURES

Limits of Confidentiality

Complete confidentiality cannot be offered to a person making a disclosure, relative or member of the public. Information given to a member of staff belongs to that agency and must be shared on a "need to know" basis. The BCUHB confidentiality policy outlines that the law permits the disclosure of any confidential information (Public Interest Disclosure Act 1998) necessary to safeguard a person in the public interest and that it may not be possible to assure a service user of absolute confidentiality because of this requirement. However, anonymity could be offered but the BCUHB may not be able to guarantee this.

The following key principles underpin confidentiality:

- Information will be shared only on a "need to know" basis
- Information will be shared only when it is in the best interest of the service user
- Confidentiality must not be confused with secrecy
- Informed consent should be obtained where possible
- Decision about who needs to know and what needs to be known should be considered on a case-by case basis.

The limits of confidentiality will thus be set out and agreed at the very beginning of the study/research. This information is included in both the Participant Information Sheet and the Consent Form.

The exact process for dealing with incidental disclosures is outlined in Figures 1 and 2.

Figure 1. Flow Chart for reporting alleged abuse

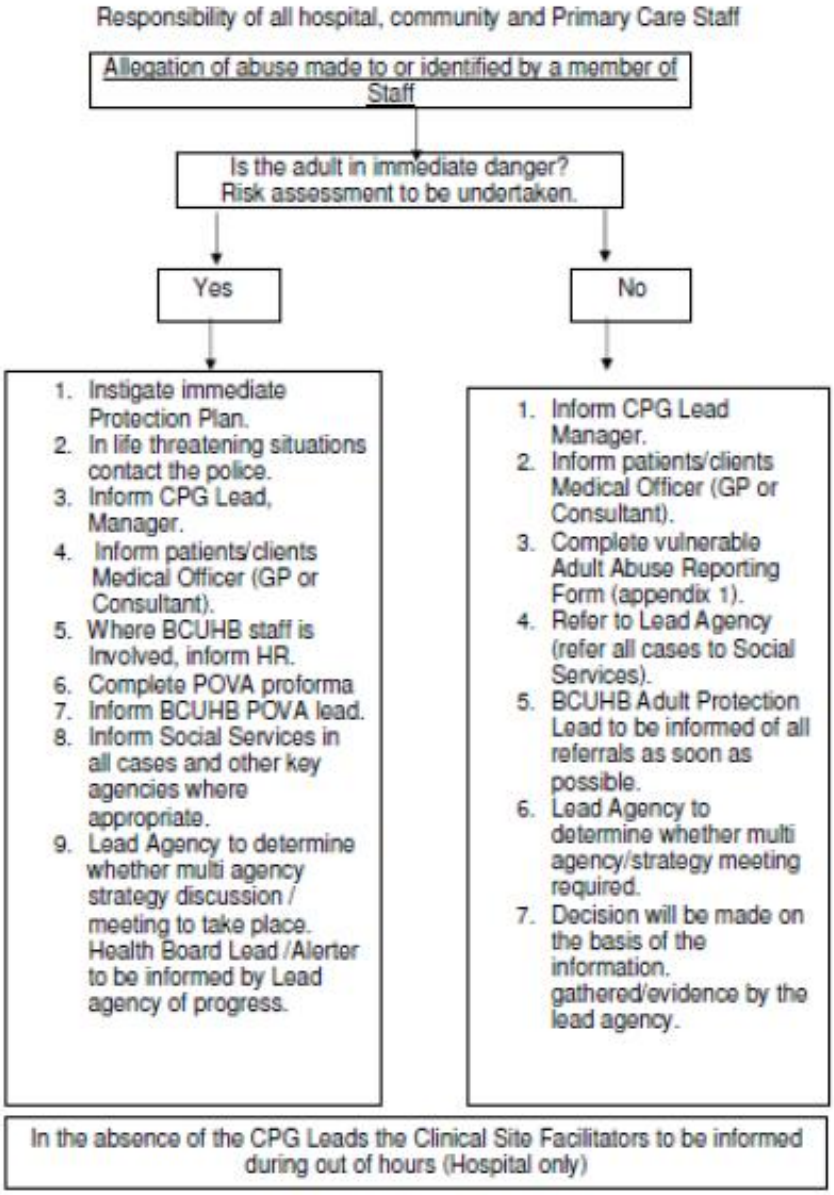
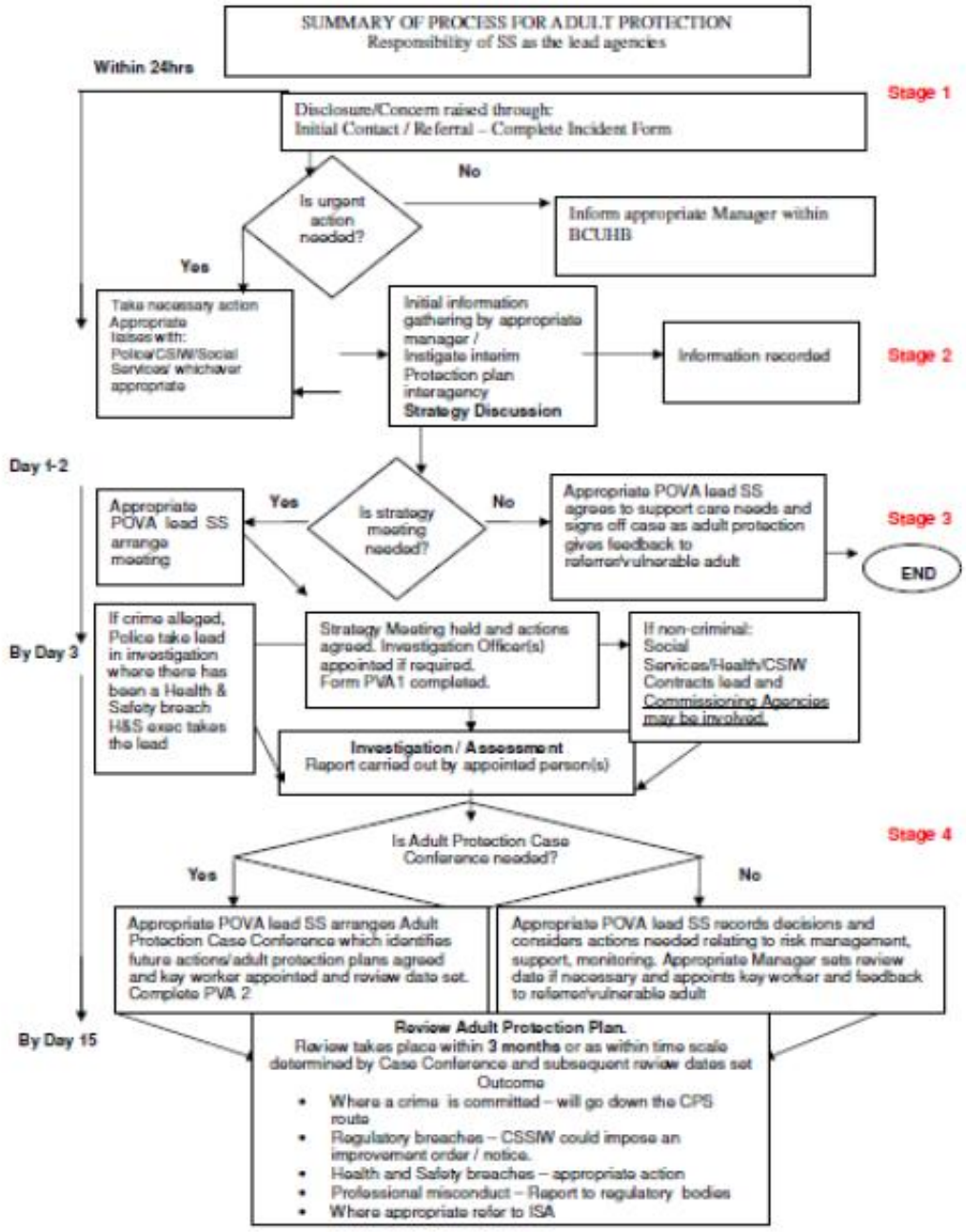


Figure 2. Flow chart summarising process for dealing with incidental disclosures



PROCESS(ES) FOR MANAGING UNANTICIPATED AND UNDUE DISTRESS

In terms of the assessment process, there is some small risk that some participants may find some of the questions mildly distressing, as they are of a potentially emotive nature. However, most of the questionnaires have been routinely and safely used as assessments with individuals with Intellectual Disabilities.

Prior to starting the assessment process, the principal investigator shall establish with the participants an agreed way of communicating if they are distressed. Should this happen, the principal investigator shall immediately halt the assessment process and address the immediate distress in situ (e.g. clinic), preferably with its immediate resolution. Additional supervision and support to address/manage this will be available from the principal investigator's supervisor. The principal investigator will subsequently ascertain whether the participant wishes to continue or not with the assessment process. If not (and/or the distress has not been satisfactorily resolved, and/or significant concerns remain), the participant shall be supported and directed to further appropriate support if required, and monitored accordingly. The principal investigator will contact the participant's lead clinician and GP, with the participant's prior consent, to inform them about the participant's current situation. Other professionals will be adequately supported and advised through appropriate means (e.g. consultation) to manage/resolve any undue distress until all parties collectively agree that this has been satisfactorily resolved.

In terms of the intervention, there is some small risk that some participants may become mildly distressed when engaging in practices to cultivate self-compassion, relating to fears/blocks/resistances to compassion identified in previous research (Gilbert et al; 2011, 2012, 2014; Pauley & McPherson, 2010; Rockliff et al, 2008). However, CFT was specifically developed to explicitly address these issues, and includes a number of therapeutic processes and procedures to formally address these issues (Gilbert et al; 2010, 2014; Duarte et al, 2014). This shall be an integral part of the intervention and incorporated into each group session, to ensure that any distress is appropriately identified, addressed, and resolved. **Participants will NOT be required to disclose or talk about specific emotionally sensitive events as part of the group, as this is not the focus of group (is primarily skills-based).**

References

Betsi Cadwaladr University Health Board (2009). *Policy and Procedures for the Protection of Vulnerable Adults (POVA).*

National Disability Authority (2009). *Ethical Guidance for research with People with Disabilities.* http://nda.ie/Policy-and-research/Research/Research-Qualtiy-Criteria/

ID NUMBER

PTOS-ID II

Psychological Therapies Outcome Scale

Intellectual Disabilities

2nd Edition

Name			
Gender	Male	Female	*Stage Completed* **S** Screening **A** Assessment **F** First Therapy Session **D** During Therapy **L** Last Therapy Session Stage ☐ Episode of Care ☐
Age			
IQ			
Reason for referral			
Date of completion			
Therapist			

Important – Please Read

Please read each question asking how the individual has felt over the last week.
Ask individual to answer 'yes' or 'no'.
If 'yes', use response scale to assist individual to record frequency of how they have felt.

	OVER THE PAST WEEK...	Not at all	A little bit	Sometimes	A lot
1	Have you been interested in doing things or meeting people?	0	1	2	3
2	Have you felt sad?	0	1	2	3
3	Have you felt angry?	0	1	2	3
4	Have you felt frightened of things or places?	0	1	2	3
5	Have you felt like you can make friends?	0	1	2	3

OVER THE PAST WEEK...		Not at all	A little bit	Some times	A lot
6	Have you felt annoyed?	0	1	2	3
7	Have you felt you are a good person?	0	1	2	3
8	Have you suddenly felt scared?	0	1	2	3
9	Have you felt like smashing things?	0	1	2	3
10	Have you felt anxious?	0	1	2	3
11	Have you been sleeping less than usual? If no, have you been sleeping more than usual?	0	1	2	3
12	Have you been able to cope with problems?	0	1	2	3
13	Have you checked things over and over again?	0	1	2	3
14	Have you looked forward to things?	0	1	2	3
15	Have you been able to stand up for yourself?	0	1	2	3

Jackson, Beail & Vlissides (2011) Psychological Therapies Outcome Scale – ID II

OVER THE PAST WEEK...		Not at all	A little bit	Some times	A lot
16	Have you felt you can do things as well as other people?	0	1	2	3
17	Have you felt faint or dizzy?	0	1	2	3
18	Have you felt like you are no good?	0	1	2	3
19	Have you felt like hitting someone?	0	1	2	3
20	Have you been able to tell people how you feel?	0	1	2	3
21	Have you stayed away from some places or things because you are frightened of them?	0	1	2	3
22	Have you been eating more than usual? If no, have you been eating less than usual?	0	1	2	3
23	Have you had a bad temper?	0	1	2	3
24	Have you felt happy with your life?	0	1	2	3

Jackson, Beail & Vlissides (2011) Psychological Therapies Outcome Scale – ID II

OVER THE PAST WEEK...		Not at all	A little bit	Some times	A lot
25	Have you thought about death or dying?	0	1	2	3
26	Have you felt people love or care about you?	0	1	2	3
27	Have you been able to show other people you love or care about them?	0	1	2	3
28	Have you felt wound up?	0	1	2	3
29	Have you felt happy?	0	1	2	3

Jackson, Beail & Vlissides (2011) Psychological Therapies Outcome Scale – ID II

PTOS-ID II: Risk Screening

	OVER THE PAST WEEK...	Not at all	A little bit	Sometimes	A lot
1	Have you hit another person?	0	1	2	3
2	Have you thought of hurting yourself?	0	1	2	3
3	Have you made plans to end your life?	0	1	2	3
4	Have you hurt yourself?	0	1	2	3
5	Have you threatened another person?	0	1	2	3

Jackson, Beail & Vlissides (2011) Psychological Therapies Outcome Scale – ID II

PTOS-ID II: Scoring

Psychological Distress	
Q2	
+	
Q3	
+	
Q4	
+	
Q6	
+	
Q8	
+	
Q9	
+	
Q10	
+	
Q11	
+	
Q17	
+	
Q18	
+	
Q19	
+	
Q21	
+	
Q22	
+	
Q23	
+	
Q25	
+	
Q28	
Total	/16
=	

Q 12 and Q 13 do not contribute to the indexes.

Positive Well-Being

Q1	
+	
Q5	
+	
Q7	
+	
Q14	
+	
Q15	
+	
Q16	
+	
Q20	
+	
Q24	
+	
Q26	
+	
Q27	
+	
Q29	
Total	
	/11
=	

SELF-COMPASSION SCALE–Short Form for Intellectual Disabilities (SCS–SF ID)

To Whom it May Concern:

Please feel free to use the Self-Compassion Scale – Short Form in your research (12 items instead of 26 items). The short scale has a near perfect correlation with the long scale when examining total scores. We do not recommend using the short form if you are interested in subscale scores, since they're less reliable with the short form. You can e-mail me with any questions you may have. The appropriate reference is listed below.

Best wishes,

Kristin Neff, Ph. D.

e-mail: kristin.neff@mail.utexas.edu

Reference:

Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the Self-Compassion Scale. *Clinical Psychology & Psychotherapy. 18*, 250-255.

Coding Key:

Self-Kindness Items: 2, 6

Self-Judgment Items: 11, 12

Common Humanity Items: 5, 10

Isolation Items: 4, 8

Mindfulness Items: 3, 7

Over-identified Items: 1, 9

Subscale scores are computed by calculating the mean of subscale item responses. To compute a total self-compassion score, reverse score the negative subscale items - self-judgment, isolation, and over-identification (i.e., 1 = 5, 2 = 4, 3 = 3, 4 = 2, 5 = 1) - then compute a total mean.

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never	Sometimes	About half of the time	Quite a lot	Almost always
1	2	3	4	5

_____1. When I get something wrong I feel like I'm no good at anything

_____2. I try to be kind to myself about the things I don't like about me

_____3. When something happens that upsets me, I try to think carefully and calmly about what has happened

_____4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.

_____5. When I get things wrong I remind myself that everyone gets things wrong sometimes

_____6. When I'm going through a hard time, I try to care of myself

_____7. When something upsets me I try to keep my emotions in balance.

_____8. When I fail at something that's important to me, I tend to feel like the only one

_____9. When I'm feeling down I tend to get stuck on thinking about what is wrong.

_____10. When I feel no good/ not good enough in some way, I try to remind myself that everyone feels like they're not good enough sometimes.

_____11. I give myself a hard time about the things I'm not good at or don't like about myself

_____12. I can't stand/accept the parts of me that I don't like.

The Social Comparison Scale

Participant No.	Administrator	Date
		/ /

1. When I am with other people I generally feel:

worse than other people

better than other people

2. When I am with other people I generally feel:

better at things

not as good at things

3. When I am with other people I generally feel:

More friendly Less friendly

4. When I am with other people I generally feel:

more shy

less shy

5. When I am with other people I generally feel:

part of the group — on my own

6. When I am with other people I generally feel:

the same different

Feasibility and Acceptability Measure

CFT-ID | Feasibility & Acceptability Measure | 03.06.2015/v1

CFT-ID Group Session Feedback

Date: **Session:** **Participant Number:**

Please tick one bock for each of the questions:

1. How much of the group did you understand today?



All of it ☐ Some of it ☐ None of it ☐

2. Was the group helpful today?



Yes ☐ No ☐ Don't know ☐

3. How helpful were the exercises (e.g. breathing, kindness practice) we did today?



Very helpful ☐ A little helpful ☐ Not helpful ☐

4. How easy was it to do the practices today?



Easy ☐ A bit hard ☐ Very hard ☐

5. Did you enjoy what we did in the group today?



Yes ☐ No ☐ Not sure ☐

Thank you for filling in the questionnaire.

Focus Group Interview Schedule

CFT-ID Interview Schedule for Focus Group

QUESTIONS

[THE MAIN QUESTIONS ARE NUMBERED IN BOLD, AND ARE THE GUIDING QUESTIONS. PLEASE FEEL FREE TO USE PROMPTS TO ELICIT FURTHER AND MORE SPECIFIC INFORMATION]

1. **What made you want to go to the group?**

2. **What did you learn from the group?**

PROMPTS:

- Could you follow the group ok?
- Was there anything in the group that you did not know before?

IF PARTICIPANTS STRUGGLE, USE FOLLOWING PROMPTS (and visual aids/prompts):

- Compassion (being kind, caring and helpful to ourselves)
- Having 'tricky' brains
- 'Not your fault' and 'all in the same boat' (common humanity)
- Three circles
- Being kind and caring rather than mean to yourself

3. **What was the most helpful part of the group and why?**

PROMPTS:

- Can you tell me how this has helped you? (*elicit examples*)
- Can you tell me how and why this had made a difference to you?
- What has it changed? What has it helped you with?
- What has it helped you do?

4. **What was the least helpful part of the group and why?**

PROMPTS:

- What did you like least?
- What might make the group better?
- What would you change about the group?
- What would you like to do more of in the group?

5. How did you find the practices/exercises you did in the group?

PROMPTS for exercises:

- In the group, you practiced lots of things like 'Calm Breathing', practicing having an 'inner kind friendly voice' to yourself, practicing being and acting as your most kind/caring/helpful (compassionate) self, and practicing imagining somebody very kind/caring/helpful (compassionate image) talking to you

PROMPTS for eliciting practice-specific information and effects:

- How did you find the practices/exercises, in general? How were the exercises for you?
- Were they easy/hard to understand?
- Were they easy/hard to do?
- How often did you use the exercises/practices?
- Which one(s) did you use/practice?
- When did you use the exercises/practices?
- How did they help you?

6. What do you think it will be like to put these things into practice in your everyday life?

PROMPTS:

- How might you do that?
- What would help you do that?

7. Do you think the group has changed the way you feel you feel about, talk to, and treat yourself?

- Can you tell or show me how (*give examples*)?

8. Would you go to the group again?

- Would you recommend the group to other people? Why?

Group Protocol

GROWING KIND MINDS:

COMPASSION FOCUSED THERAPY GROUP FOR PEOPLE WITH

INTELLECTUAL DISABILITIES (CFT-ID)

GROUP PROTOCOL v1

Developed by Neil Clapton & Jonathan Williams

Acknowledgements

The investigators would like to offer their sincerest thanks, gratitude and appreciation to the following individuals for their collective wisdom and expertise, which has contributed greatly to the development of this protocol: Professor Paul Gilbert, Russell Kolts, Chris Irons, Michelle Cree, Charlie Heriot-Maitland, Tobyn Bell, Andrew Rayner, Helen Heapy, and Julia Frearson.

About CFT

Compassion Focused Therapy (CFT; Gilbert, 2005, 2009, 2010) was originally specifically developed for clients with mental health difficulties characterised by high shame and self-criticism. CFT explicitly targets the development of affiliative emotion that helps to engage with and regulate difficult emotions, and tone up positive emotions of safeness, contentment, and well-being. This is supported by research indicating that compassion training can have wide-ranging physiological and psychological benefits, including changes at a neural and emotional level (Klimecki et al, 2013; Weng et al, 2013, Jazaieri et al, 2013), and is thus an eminently trainable skill. This is likely enhanced in a group setting, as central to CFT is the creation of affiliative contexts to share, de-shame, validate, soothe, and encourage (Bates, 2005). CFT has been shown to be feasible, acceptable and efficacious in a

group format for individuals with wide-ranging and complex mental health difficulties (Gilbert & Procter, 2006; Judge et al, 2012; Lucre & Corten, 2013), and has begun to be adapted into briefer group therapies such as for acute psychiatric inpatients, where it has also shown to be feasible and efficacious (Heriot-Maitland, 2014).

Outline of Intervention

CFT focuses on helping people access and stimulate affiliative motives, emotions and competencies underpinning compassion that play important roles in threat regulation, well-being, and prosocial behaviour (Gilbert, 2014). These include interventions such as the use of breathing, posture, facial expressions and voice tones to help balance the autonomic nervous system through parasympathetic activation/stimulation. This further involves the teaching of a series of compassion cultivation exercises that involve attention training, practising mindfulness, mentalizing, compassionate self-identity cultivation, the use of compassionate imagery, and enacting compassionate behaviours on a regular basis. These fall under the umbrella of Compassionate Mind Training (Gilbert, 2010), which is designed to cultivate and develop the various subcomponents and competencies of the two psychologies of compassion – *engagement* with and *alleviation/prevention* of suffering (Gilbert & Choden, 2013).

Session Outline

- **SESSION 1: 'Welcoming each other!'**
    (1) Introduction to group members and facilitators
    (2) Set ground rules
    (3) Repeat/reiterate purpose of group
    (4) Brief introduction to the concept of compassion (as 'kindness' and 'true strength'): practical exercise – what it is and isn't, how it might be helpful, fears about developing; brief introduction to principles of CFT
    (5) Establish group 'compassionate mind'

- **SESSION 2: 'Life is Hard – It's Not Your Fault!'**
    (1) Tricky brain
    (2) 'Not your fault' concept
    (3) Practical exercise: demonstration of importance of mindfulness & slowing down (beaker exercise)
    (4) Introduction to 'Calm Breathing' (Mindful SBR practice)

- **SESSION 3: 'Getting to know our brains and bodies better'**
    (1) Introduction to the 'Three Circles' model of CFT
    (2) Practical exercise: Three circles and how they affect our minds and bodies (motives, emotions, attention, thoughts, bodily urges, behaviours)
    (3) Talk about 'stress' related to threats, relate to the three circles

(4) Practical exercise: Beginning to move out of the red (threat) and into the green (affiliative/soothing) → SBR practice
(5) Practical exercise: Beginning to practice using our inner warm, kind, friendly voice

- **SESSION 4: 'Becoming our own Best Friend'**
  (1) Exploring the power of our minds (thoughts, images, self-relating)
  (2) Exploration of self-compassion: distinguish differences between self-criticism and self-compassion
  (3) Practical exercise: feeling the difference between being critical and compassionate to ourselves
  (4) Fears/blocks/resistances to compassion for self/others/from others
  (5) Practical exercise: Beginning to carry around a friend in our own head
  (6) Practical exercise: 'Compassionate Self', 'Compassionate Ideal'

- **SESSION 5: 'Let It Go! Being Here Right Now, and Looking for the Good'**
  (1) Letting go and focusing on what is helpful
  (2) Being brave
  (3) Being kind to others
  (4) Gratitude

- **SESSION 6: 'Keeping Kindness Going' – Review and Maintenance**

SESSION 1: "Welcoming Each Other!" – Introduction to the group

(1) Names and Introductions

- Give out name tags
- What has brought them here today (why they are here?)
- What would they like to get out of the group, and what are they worried about in terms of being in the group (hopes and fears)?

(2) (Re) Introduce the purpose of the group

(3) Establish group rules [USE FLIPCHART]

(4) GROUP EXERCISE: Introduction to concept of compassion [USE FLIPCHART]

- Elicit participants' understanding and meaning

- Clarify what compassion is/isn't
- What do they like about it? What do they not like about it?

(5) GROUP EXERCISE: Initial Fears/Blocks/Resistances (FBRs) to compassion [USE FLIPCHART]

- What might people's FBRs be?
- Where might these have started/come from?
- What would it be like if we could overcome these blocks? (compassionately validate FBRS, whilst stressing that we will be helping to overcome these blocks in the group, and that is an essential part of the practice)

SESSION 2: "Life is Hard – It's Not Your Fault!"

(1) Psychoeducation about the nature of human existence – life is hard

- The three noble truths of CFT: the flow of life, the tragedy of human existence, the socially shaped nature of ourselves
- 'Not your fault': didn't choose to have this brain, these emotions, your experiences, have an LD → cant change these, BUT is our responsibility about how to best deal with (do the best we can)
- Introduce concept of 'Common Humanity' – we are all in the same boat together
- ***Practical exercise:*** blame vs. no blame, resistance vs. acceptance

(2) Psychoeducation about our evolved 'tricky' brains

- Introducing this as understanding how our brain works, so we can understand ourselves better
- Playfully explore concept of 'Old Brain/New Brain' interactions and loops

(3) Mindful breathing as a first step to being kinder to ourselves

- ***Practical exercise:*** the threat system as the 'magnet of the mind'

- Exploration that attention is moveable: we can move it (like a spotlight), and what we choose to focus on affects how we feel
- Exploration of why it is important to slow down and become aware of what is going on in our mind
- ***Practical exercise:*** 'Clear Mind Activity' demonstration (beaker of water and soda exercise), and practicing 'Calm Breathing' (Mindful Soothing Breathing Rhythm – SBR) → learning to be 'strong and still, like a mountain'

(4) Beginning to treat ourselves more kindly

- ***Practical exercise:*** Beginning to practice using our inner warm, kind, friendly voice

(5) Set home/personal practice

<u>SESSION 3: 'Getting to know our brains and bodies better' – Intro to 3 Circles</u>

(1) Introduction to the 'Three Circles' Model of CFT

- ***Practical exercise:*** Three circles and how they affect our minds and bodies (motives, emotions, attention, thoughts, bodily urges, behaviours) – stepping into each three
- Talk about 'stress' related to threats, relate to the three circles
- ***Practical exercise:*** how big are our own three circles? DRAWING! → What might have shaped these? What might have made them unbalanced (de-shame and validate)
- Re-iterate the goal of the CFT group: to re-balance the systems, particularly building up and using the green system to do so (can't get rid of threat system/emotions, have to learn how to compassionately respond to and manage them so we are calmer, peaceful, content, strong/brave, less frightened or down all the time, feel less alone)

(2) The many different parts of us

- Exploration of how we can have many different reactions to things, and that these 'selves' can take control of our minds and 'run the show'

- Explain how we can train/build up the kind, helpful, caring part of ourselves (the self that we would like to be), and explore as a group how/why this might be helpful

(3) Helping ourselves move out of the Red and into the Green

- Re-iterate the importance of practice/training: like working out at the gym, training for a marathon/climb a mountain; like a workout/ physio for the mind (treading a new path – forest example)
- ***Practical exercise:*** Re-visit and re-practice 'Calm Breathing' (SBR)
- ***Practical exercise:*** Practicing becoming the compassionate self (method acting)

(4) Helping each other be kinder (compassionate) to ourselves

- ***Practical exercise:*** use previous exercise to practice being compassionate to each other, and how they would respond to difficult situations in their lives

(5) Set home/personal practice

SESSION 4: 'Becoming our own Best Friend' – Behavioural and Imagery Practice

(1) Exploring the power of our minds (thoughts, images, self-relating)

- ***Practical exercise:*** how internal and external cues activate the same emotional systems (cake, winning the lottery, bullying, kindness)
- Explore how this can not only help calm and soothe us when distressed, but help us face difficult things and flourish

(2) Exploration of self compassion: distinguishing the difference between self-criticism and compassionate self-correction

- ***Practical exercise:*** feeling the difference between being critical and compassionate to ourselves → model to group (facilitators exploring a difficult situation, demonstrating the response of the critical self and the compassionate self), sit facilitator in middle and encourage members to take it in turns being (briefly) self-critic and (more extensively) compassionate self

(3) More practice becoming our kindest (compassionate), best possible self

- Explore qualities we might need to develop, how might we go about doing that (flip chart)
- Re-explore fears/blocks/resistances to compassion for self/others/from others
- ***Practical exercise:*** giving and receiving compassion in pairs
- ***Practical exercise:*** beginning to carry around a friend in our own head

(4) Creating our own Compassionate Ideal Other to help calm and soothe us

- Explore how we can use this to generate feelings of warmth and kindness (does not matter if is not real – is stimulating systems in our brain)

(5) Learning to notice and appreciate the good in us

- Learning to notice what we are good at, our own unique strengths
- Emphasise our common humanity that we all have strengths and weakness
- ***Practical exercise***: learning to take joy in ourselves, what we are good at, our successes (how this helps us be happy and grow)

(6) Set personal/home practice

SESSION 5: 'Let It Go! Being here right now, and looking for the good'

(1) Being brave (how kindness helps us be strong and brave – courageous)

- Explore how being kind to ourselves can help us face and do difficult/new things, overcome our fears
- Explore how kindness can help us (appropriately) stand up for ourselves/get what we need

(2) Letting Go and focusing on what is helpful

- Explore why this is helpful, but can be very difficult!
- ***Practical exercise:*** red and green balloons – letting go of unhelpful thoughts/emotions/reactions (red balloons); finding, noticing, and keeping hold of helpful ones (green balloons)

(3) Being Kind to Others

- Explore how and why this is good for us and others
- ***Practical exercise***: doing Random Acts of Kindness for others

(4) Gratitude practice

- ***Practical exercise***: think of three things in your life that make you feel happy or lucky to have (try and do this every day for the next week – what do you notice?)
- ***Practical exercise:*** Practicing gratitude with each other – tell another person in the group what you like about them, what you think their strengths are, and why you have liked having them in the group

(5) Set personal/home practice

SESSION 6: 'Keeping Kindness Going' – Review and Maintenance

(1) Review what has been learnt in group

- Review concepts
- Review exercises
- Brief exploration around what people think they have learnt, how the practices have gone, what they have found useful/helpful or hard
- Encourage to explore if they have noticed any changes

(2) Maintenance

- Explore ways of keeping kindness going in their day-to-day lives
- Share ideas around how they might do this
- Reiterate the importance of PRACTICE, PRACTICE, PRACTICE!
- Explore how this might continue to be helpful in their life – what changes, what are the consequences, what can they do more of, how might life be better?
- Workbooks
- Explore helpful relationships: how they can use others they trust as compassionate coaches

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COMPASSION FOCUSED THERAPY (CFT) GROUP

GROWING KIND MINDS

Building true inner strength

..... WORKBOOK

SESSION 1

WELCOME and INTRODUCTION

This group will help you learn how to be **kind, caring, and helpful** to yourself. This is something we call

COMPASSION

The group will involve practicing lots of different ways of being kind, caring and helpful (compassionate) to yourself, and learning how this can be helpful and useful in life.

Together we will also look at how and why our minds work the way they do, learn about our emotions (feelings), and how to cope with them in a helpful way.

What is Compassion?

Compassion (being kind, caring and helpful to ourselves) is....

- A type of strength, that helps us face hard and painful things, and how to deal with them

- Being nice to yourself instead of being mean to yourself

- Feeling like you are linked up with people and not alone (on your own)

- Being focused on one thing at a time in the here and now, and not getting stuck on things from the past or in the future

- Focused on being well and content (peaceful), not just seeking excitement and happiness (pleasure)

Exercise 1

How might being kinder to ourselves be helpful?

Think of some ways this might help you:

How might being kinder to ourselves be hard?

Think of some reasons (for example, worries) that might make this hard to do:

The Benefits of Compassion

Learning to be more compassionate will make the following things a bit better:

- What you feel and think about yourself
- How you talk to and treat yourself

- How you deal with life problems (the ups and downs of life)

- How you get along with other people

- How you choose your goals and work towards them

HOME PRACTICE WEEK 1

(1) Practicing having a friendly voice to ourselves

- Sit up as straight as you can, with your feet flat on the floor. You can close your eyes if you want.

- Take a moment to take a few (maybe three) slow deep breaths

- First of all, keep a neutral face and voice, and say "hello" to yourself.

- See if you can notice how this makes you feel in your body.

- Now, try and bring a half-smile to your face (gentle, warm, friendly) and in a warm friendly voice, say "hello" to yourself.

- Again, see if you can notice how this makes you feel in your body.

Maybe try practicing the friendly voice and smile when you wake up in the morning.

If you want, with your inner friendly voice, ask yourself:

"How would I like to treat myself today?"

Then, if it feels right, maybe say to yourself:

"May I treat myself with kindness today"

"May I find some joy today"

"May I find some peace today"

If you can, see if you can start to notice when you have been (or tried to be) kind, caring and helpful to yourself in the day.

Write it down below if you want (think about: what you were doing, how you were feeling, how you tried to be kind/caring/helpful, and how it made you feel):

SESSION 2

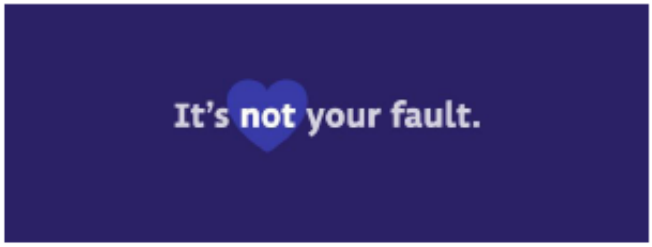
LIFE IS HARD – IT IS NOT YOUR FAULT!

Sometimes we give ourselves a hard time and beat ourselves up over things that are not really our fault:

- We didn't chose to be born, or what time in history we were born

- We didn't choose our brains and how they work – we didn't choose our emotions, or our basic human desires and needs

- We didn't choose our body and how it works



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We are all in the same boat!

- We all want to be happy

- We all don't want to suffer

- Even though things are not our fault, we do have to work out how best to deal with things

- This is why we are learning compassion (being kind caring and helpful to ourselves): it helps us survive, grow and live as well as we can

HOME PRACTICE WEEK 2

(1) Practicing 'Calm Breathing'

This is something you can practice to help you when you are stressed, angry, frightened, upset.

This is how it can help:

- Notice what you are feeling and thinking, without getting caught up in them

- Slow down your body and mind...

- So you can think more clearly...

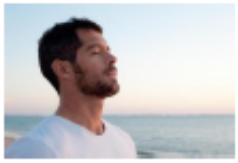
- And choose how to respond to whatever it is...

- With a calm, kind mind

Here's how to do it:

- Sit up as straight as you can, with your feet flat on the floor. You can close your eyes if you want.

- Gently focus on your breathing (and the sensations that go with it), noticing and following it as it comes in through your nose, down into your belly, and rises back through your body and out of your nose.



- Start to breathe a little more slowly and deeply than you would normally.

- When you breathe out, see if you can focus on the sense of slowing down – like a fast flowing river as it reaches a wide open lake.

- See if you can start to notice feeling a little heavier – as if you are becoming strong, still, and stable, like a mountain.

- You may find that thoughts and feelings pop into your mind. This is OK and very normal. You are not trying to get rid of anything.

- Every time this happens, gently notice it has happened, see if you can let them go free, and gently return and rest your attention back to the breathing (and the calm sensations that come with it).

- Try this for a few minutes, and then (if you closed them) open your eyes to finish.

TIP: It is good to practice this when you are not stressed or upset, so that you get used to it and then it is easier to do when you really need it!

(2) Continue practicing using the inner kind, friendly voice to yourself (from Week 1)

- Notice when you are being hard/mean to yourself, or beating yourself up
- Practice 'Calm Breathing'
- Then try being kind to yourself by using your inner kind friendly voice
  - Think what kind, caring, helpful things you could say to yourself
  - Notice how this makes you feel after you have tried it out

SESSION 3

UNDERSTANDING OUR BRAINS AND BODIES BETTER

We have different bits of our brain that make us feel and think certain things.

Our THREAT system (the red circle) is designed to pick up on things that might be harmful, dangerous or painful to us in some way.

It works in a 'Better Safe Than Sorry' way – this means that it kicks in very quickly. It is trying to protect us from something threatening and keep us safe. It easily makes mistakes!

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When we are in our THREAT system (red circle):


- We feel lots of difficult emotions (like anxiety/fear, anger, sadness), and these can take over us

- Our bodies often start to 'speed up' – our heart beats faster, are breathing speeds up, and the muscles in our body become tense

- We feel constantly threatened – our thoughts and what we focus on are threats (something bad happening)

- We don't see many options – so we can feel trapped

- We can feel like we want to run away, fight back, or 'shut down' (give in and give up)

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Our DRIVE system (the blue circle) gives us energy to do things and get things that will help us survive.

It makes us feel excited and feel good when we get what we want or do well at something.

However, we can feel frustrated when we cant get what we want, or lose all our energy and joy when we feel too threatened and alone.

Our SOOTHING system (the green circle) helps us to feel safe, calm, content, cared for, and connected to others.

It is this part of our brain that helps calm and soothe us. It balances us out, so we feel less threatened (stressed, frightened, angry), and gives us the strength to cope.

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When we (or others) are kind, caring and helpful (compassionate) to ourselves, it switches this part of our brain on.

When we are in our SOOTHING system (green circle):

- We still feel lots of difficult emotions, but they **don't** take over us – we feel safe with them

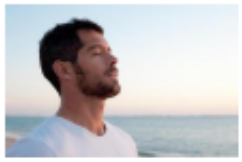

- Our bodies start to slow down – our breathing slows down, our heart slows down, and we can feel calmer, relaxed and more peaceful


- We can more easily focus on what is helpful – we can see many options, and decide what is best

- We feel **connected** to others – we feel similar to others, we feel less alone, and we can turn to others for help if we need it


HOME PRACTICE WEEK 3

(1) Practicing being our kinder, caring, helpful (compassionate) self



- Start with the 'Calm Breathing' we practiced last week...

- ...until you can feel your mind and body slowing down – like a fast flowing river as it reaches a wide open lake...

- ...feeling yourself becoming more strong, still, and stable, like a mountain.

- Now, try and bring a half-smile to your face (gentle, warm, friendly) and in a warm friendly voice, say "hello" to yourself.

- Now, in your mind, imagine that you are:
  - Warm, friendly and kind
  - Calm and wise (this means understanding and giving helpful advice)
  - Strong, confident and patient (and that you can deal with any difficulty that comes your way)

- Deeply caring and wanting to help you suffer less and feel safe (like a best friend)

- How would this part of you speak? What would its tone of voice sound like?

- How would it try to help you? What kind of things would it say to help you feel safe?

- How would it try to help you feel supported? How would it help you face something difficult?

(2) Continue practicing using the inner kind, friendly voice to yourself

- Notice when you are being hard/mean to yourself, or beating yourself up
  - Notice how this makes you feel

- Practice 'Calm Breathing'

- Then try being kind to yourself by practicing being your **'Compassionate Self'**
  - Using your inner kind friendly voice
  - Think what kind, caring, helpful things you could say to yourself
  - Notice how this makes you feel after you have tried it out

SESSION 4

BECOMING OUR OWN BEST FRIEND:

Practice being our 'Compassionate Self'

We have spent a lot of time understanding how the way we talk to and treat ourselves (the 'voice in our head or on our shoulder') effects how we feel.

This week, we are going to carry on practicing being the kind, caring, helpful (compassionate) part of ourselves.

This can help us to:

- Calm and soothe ourselves
- Understand scary or difficult feelings
- Give us strength to face, deal with and do hard things (be brave)

We do this by practicing being this way (a bit like if we were an actor in a film or musical), so we get used to being this way ***to ourselves***.

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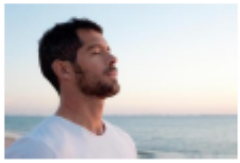
Then, when we are stressed, having difficult feelings, or finding things hard, we can use this part of us to helps us out (it 'pops up' and is there for us, like a good friend).

Practicing being our kinder, caring, helpful (compassionate) self

- Start with the 'Calm Breathing' we have been practicing...



- ...until you can feel your mind and body slowing down – like a fast flowing river as it reaches a wide open lake...

- ...feeling yourself becoming more strong, still, and stable, like a mountain.

- Now, try and bring a half-smile to your face (gentle, warm, friendly)

- Now, in your mind, imagine that you are:
  - Warm, friendly and kind

- Calm and wise (this means understanding and giving helpful advice)
- Strong, confident and patient (and that you can deal with any difficulty that comes your way)
- Deeply caring and wanting to help you suffer less and feel safe (like a best friend)

- How would this part of you speak? What would its tone of voice sound like?

- How would it try to help you? What kind of things would it say to help you feel safe?

- How would it try to help you feel supported? How would it help you face something difficult?

Three helpful things that your Compassionate Self remembers:

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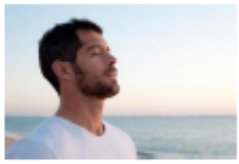
We can also practice imagining a compassionate person or thing in our head that speaks to us in a kind, helpful, caring and supportive way. This can be whatever you want it to be (human, animal), it is whatever is helpful to you. If it helps, you can also draw this or find a picture that best fits.

Here's how to do it:

- Start with the 'Calm Breathing', so your mind and body slows down. Close your eyes if it helps...



- Imagine that someone or something is smiling at you
- This someone or something is:
  - Kind and warm towards you
  - Strong and protective towards you
  - Is wise, understands you, and gives you good advice

- Allow a picture to come into your mind of someone or something:
  - What do they look like? Are they human or not?
  - Are they young or old? Are they male or female?
  - What do they sound, smell, and feel like?

- How would you like them to behave towards you?
- You can imagine this kind person or thing whenever you need to
- Come back to your breathing, and open your eyes

HOME PRACTICE WEEK 4:
Compassion Practice Diary

Over the next two weeks, see if you can fill in the diary. Write in which practice you did, what time, how you felt before and after.

Day and Time	Type of Practice and How Long	How did you feel before and after? What was helpful?
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Day and time	Type of Practice and How Long	How did you feel before and after? What was helpful?
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

SESSION 5

BEING BRAVE, LETTING GO,

and FINDING THE GOOD:

Using our 'Compassionate Self' to face and do hard things that help us grow and live well

This week, we are going to carry on practicing being the kind, caring, helpful (compassionate) part of ourselves. We are going to use it to help us:

- Be BRAVE, by facing and doing hard, difficult and frigthening things

- Stand up for ourselves

- Accept and let go of painful things so that we dont suffer as much, and live our lives right now

- Notice, remember and do things that make us and others feel safer, calmer, peaceful, and happier

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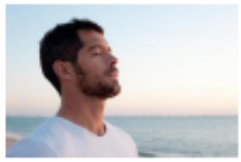
Using our Compassionate (kind, caring, helpful) Self or Image to face and do something hard (be BRAVE)

- Start with the 'Calm Breathing' we have been practicing...



- ...until you can feel your mind and body slowing down – like a fast flowing river as it reaches a wide open lake...

- ...feeling yourself becoming more strong, still, and stable, like a mountain.

- Take a few minutes to 'get into' your compassionate self, or bring your compassionate image into your mind. Remember the things that it has:

  - Strength and confidence
  - Is kind, caring, warm and friendly (has kind feelings, kind thoughts, and speaks kind words)

  - Is very wise (understands, knows the right thing to do, and knows what helps – gives helpful advice)

- Now, think of something you find hard to do, but would like to do
  - How would your compassionate self or image help you face this?
  - What would it say to you (and how would it say it)?
  - What would it help you to do? How would it help you do this?

We can also use our Compassionate Self or Image to help us STAND UP FOR OURSELVES (what is called 'assertive').

When we practice this, our Compassionate Self can:

- Speak our thoughts and feelings clearly and confidently
- Ask for what we need and want clearly and confidently
- Help us to say 'no' when we need to
- Be honest, whilst caring for the feelings of others
- Listen and understand, but also speak up when it needs to

We can also use our Compassionate Self or Image to help us accept and let go of difficult and painful things that we get 'stuck' on (like thoughts, feelings, memories).

FINDING AND DOING GOOD: KINDNESS AND GRATITUDE

Kindness (and being kind to ourselves and other people) is really important, because:

- It makes us happier
- It gives us healthier hearts
- It makes for better relationships (we feel more connected)
- It spreads to others and 'catches on'

Two things you could try that might be helpful are:

1. Spending 5 minutes remembering kindnesses that happened during the day
2. Do at least one act of kindness to yourself and someone else every day – and notice how these practices make you feel

Gratitude (noticing and being thankful for good and helpful things we have in our lives) can also help us feel more balanced, safer, happier, and content (peaceful).

See if you can think of three things each day that you feel lucky to have, that give you joy, peace, and happiness:

1. .....
2. .....
3. .....

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HOME PRACTICE WEEK 5:
Compassion Practice Diary

Over the next two weeks, see if you can fill in the diary. Write in which practice you did, what time, how you felt before and after.

Day and time	Type of Practice and How Long	How did you feel before and after? What was helpful?
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

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Day and time	Type of Practice and How Long	How did you feel before and after? What was helpful?
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

SESSION 6

KEEPING KINDNESS GOING

Over the past few weeks, we have learnt lots about this thing called 'compassion' (being kind, caring, and helpful).

We have also practiced lots of different ways of being this way towards ourselves, instead of beating ourselves up and saying mean things to ourselves.

Together we have learnt that:

- Being kind, caring and helpful (compassionate) to ourselves) 'turns on' and builds up our GREEN system

- This turns down our RED system, by calming and soothing us when we feel threatened (stressed, upset, angry, anxious)

- It also helps us be brave, by facing and doing hard, difficult and frigthening things. This can help us do things that are good for us and make us feel good about ourselves (turns on the BLUE circle)

- So a lot of what we have practiced together is to help us notice, remember and do things that make us feel safer, calmer, more peaceful, and happier.

Here are a few more practices we can do every day to help us be kinder to ourselves, and helps us out when we are struggling with something.

Practice being our Compassionate Self in the mirror

- Take a look at yourself in the mirror
  - Notice how you are feeling

- Practice being your 'Compassionate Self'
  - Warm, friendly face and voice
  - Half-smile

- Practice saying some kind, caring, helpful things to yourself

- Notice how it makes you feel

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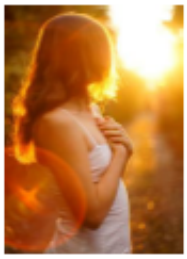
Hand on Heart Practice

- Start with some 'Calm Breathing'

- Put your hand(s) over your heart
  - Feel the warmth of your hands or touch over your chest

- In a kind, warm, friendly voice say to yourself:
  (1) "This hurts", "this is pain", or "this is stress"
  (2) "Suffering is part of life" or "I'm not alone, other people feels this way too"
  (3) "May I be kind to myself"



- Notice how it makes you feel

Some Ideas on how to 'Keep Compassion Going'

It is really important to keep practicing what we have learnt together in the group. Sometimes the hardest thing to do is to remember to use the stuff we have learned!

Here are some ideas to help us use our compassion skills:

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Friendly Reminders

- Objects
  - A stone, pebble, key ring

- Kindness Cards
  - To carry around with you

- Make it a habit...!
  - Pick a time every day to do one of the practices
  - Write on a calendar/diary/post-it, use a mobile phone to remind you!

See if you can think of any ideas that might help you remember to practice and use your compassion skills in your life:

.....

.....

and remember:

GENERAL APPENDICES

General Appendix 1. Annotated Extract from Focus Group Transcript

(I) So I guess I'm just gonna ask the three of you really like what made you want to come to this group in the first place I spose. I don't know (brief pause) if you've got any thoughts on that?

(P3) To make me feel better about myself

(I) Ok

(P3) And other people as well

(I) Yeah. "To make you feel better about yourself", and and

(P3) Other people

(I) And to feel better about other people?

(P3) Yeah

(I) Ok. Ok. Thank you

(P4) Yeah, I think the same as well. It's like, you've been, I've been beating myself up for such a long time, and even the last, forever...I wanted, I didn't...although I knew people felt the same way I did, anxious and scared and depressed and fed up, I always used to beat myself up to the point where I didn't wanna be here anymore.

(I) Uhm

(P4) And this course was, erm, suggested to me, I first thought "naaah, not another one!" Cos I've been on courses before

(I) Oh, why you've been on courses before?

(P4) Not THIS one! I've been on erm confidence courses before

(I) Yeah

(P4) And that didn't go down very well, cos the people that were in the course actually lived in the same area that I did, and went to the same, hung around the same neighbourhood that I did

(I) Oh okay

(P4) Which wasn't very good, because what everyone said in the group kind of over-spilled into my personal life, which wasn't good either.

(I) Uhm

(P4) But I missed the first, the first group of this I missed

(I) Okay

(P4) Um, and when it was suggested to me again, uh had a word with my friend and she said, "well you know, try it, you don't know what will happen until you try it." And to be honest I'm glad I did

(I) Okay

Comment [NEC1]: Talking about motivation(s) for attending, specifically wanting to feel better about the self (CODE 1)

Comment [NEC2]: Talking about motivation(s) for attending, specifically talking about wanting to change how they feel about/relate to others (CODE 2)

Comment [NEC3]: Agreement with wanting to feel better about the self (CODE 1), and how they feel about/relate to others (CODE 2)

Comment [NEC4]: Talking about wanting to be less self-critical (CODE 4); talking about engaging in self-criticism, and the negative impact of shame & self-criticism (CODE 5)

Comment [NEC5]: Talking about anxieties, doubts, and fears around attending the group (CODE 6)

Comment [NEC6]: Talking about negative/aversive previous experiences of attending other (therapeutic) groups (CODE 7)

Comment [NEC7]: Talking about how encouragement from others helped them (and feel more motivated) to attend the group (CODE 8)

1

(P4) Because it has, it has helped me quite a lot. I mean, if you'd have been here day one like Xxx said

(I) Yeah

(P4) I was, I never shut up! And then, I…I didn't think for one minute that I'd say anything

(I) Okay

(P4) But I didn't shut up!

(I) Okay! So I'm gonna come back to that, because that's really important, thank you yeah. So it's a bit like, people had said "why don't you give it a go?", and then you gave it a go, and

(P4) I'm glad I did

(I) And you're glad you did. Okay, I'll find out a bit more about why you're glad in a minute if that's okay?

(S3) I think, I think it's good that (brief pause of 2 seconds) yeah, I would say six strangers?

(I) Yeah? Yeah, exactly

(S3) And, they all open up to each other

(I) Yeah

(S3) Which you probably wouldn't do with your closest friends, you know what I mean?

(P4) Yeah

(I) Yeah, Yeah

(S3) So, because, because no one judges anyone

(P4) Exactly

(S3) That's, that's

(I) Yeah, no one judges anyone

(S3) That's a good thing that is

(I) That's, that's really important, thank you. How about you P6 is it? Any thoughts on why you decided to come along? I know it was suggested to you wasn't it? But you had a choice whether you wanted to come or not

(P6) Uh huh. I got, I got to the stage where I got fed, fed up of lock, lock, locking me in my room, not socialising, wanted to be a calmer person, so so I went

(I) Okay. So the idea that you wanted to be a calmer person?

(P6) Yeah

Comment [NEC8]: Talking about non-specific benefits of attending the group CODE 9

Comment [NEC9]: Talking about a sense of safeness and confidence to express themselves? CODE 10

Comment [NEC10]: Talking about how the encouragement and support of others to attend was ultimately helpful and beneficial in the long-term CODE 8

Comment [NEC11]: Supporters/carers talking about how the safe atmosphere of the group engendered a sense of mutual trust and openness → KEEP SEPARATE FROM PARTICIPANTS' COMMENTS/ANALYSIS

Comment [NEC12]: Talking about motivation(s) for attending, specifically how they felt about themselves prior, and the type of person they wanted to be CODE 1

(I) Okay

(P6) I thought its not help, helping locking myself in my room cos you wouldn't, wouldn't want a life at the end [?inaudible? → see 3 mins 25 secs], because it was getting to the stage where all of my friends were getting upset

(I) Uhm? Okay, so you noticed you were locking yourself away, and, but you wanted to be a calm person?

(P6) And, and all my friends suggested that I should go to group because they, they said they were getting a bit fed up of me being negative

(I) Okay

(P6) So, so I'm not that negative like I used to be

(I) So other people had noticed

(P6) Yeah

(I) that you were starting to think negatively? Okay, that's great. Okay well thank you, that's that's some really good reasons. Okay. Okey dokey. So I'm just putting up what the question is there, but you don't, we don't really need to worry about that. Okay, so this is the bit that you talked a bit about already P4, its basically "what did you learn from the group?" So, you've said a little bit already, haven't you? So, do you, can you kinda say that to me again, and sort of explain to me what it is that you you think you...

(P4) Its like, you're not, you're not on your own. You know, there are other people that are going through the same thing, and you know you can...you can find it in, in yourself to be nice to yourself, to be nice to other people

(I) Uh huh

(P4) Instead of being the one that (brief pause)...you're beating yourself up, cos the way I was, I was proper (brief pause)...I was horrible to me self, and

(I) Yeah?

(P4) Like, like I said to Neil, I would rather me be nasty to myself and beat myself up in the head, than let someone else do it

(I) Like, you're getting in there first?!? Yeah, yeah?!?

(P4) Yeah. And, even though, if, like you were standing there now (brief pause of about 3 seconds)...I, I used to get really anxious and really really, if I was in a meeting anywhere I'd be effin' and jeffin' at them, cos I wouldn't understand what they were saying, and then all of a sudden they're going "nasir nair nair nair nair [finger wagging, pointing], don't do this, don't do that" and I'd be like "Argh, argh!" And because I, I didn't understand what was going on in my own head, never mind what they were saying, I was kicking off

Comment [NEC13]: Talking about motivation(s) for attending, specifically what they would like to change about themselves [CODE 1]; problems in their lives as a result of emotional difficulties they experience [CODE 3 & CODE 1]

Comment [NEC14]: Talk about extrinsic (external) motivators for attending the group [CODE 6]; perception of pressure/threats/judgements from others rather than outright support?

Comment [NEC15]: Talking about changes in sense of self and outlook (positive emotional changes), specifically being and feeling less negative (about the self and others?) [CODE 7]

Comment [NEC16]: Talking about how the group/group process helped them to feel less alone with their difficulties/suffering [CODE 12]; increased sense of common humanity, less shame???

Comment [NEC17]: Talking about feeling more able to be kind to the self and others [CODE 11] → increased self & other compassion (positive changes in self-to-self & self-to-other relating)???

Comment [NEC18]: Talking about wanting to be less self-critical [CODE 4], engaging in self-criticism [CODE 5], and becoming less self-critical [CODE 18]

Comment [NEC19]: Talking about reasons for being self-critical [CODE 14]; related to its development, underlying functions, and fears about giving it up???

Comment [NEC20]: Talking about engaging in self-criticism, situations/events in which this would occur or in response to [CODE 5]

(I) Right

(P4) And getting really angry with them, and swearing and screaming at them. And then, coming out of that meeting and beating myself up again. So, it was like, I was on the floor before you knew it. And, through some good help and some good people, I have managed [brief pause approx. 3 seconds]...I'd say [chuckles], erm, I've managed to realise that, that I'm not on my own. I have got people who, who are gonna be there to support me and help me change, to be the person I wanna be, cos I've I've always been nice, but I just don't, I'm just not nice to myself

(I) Yeah?

(P4) But this group, it...it showed me that, even although when I first did the breathing I thought "What is he on?!?"

(I) Yeah! Ha ha!

(P4) Thinking that, ha ha, you know, "This is daft!" But once I, once I let myself do it, it was kind of relaxing, and it does, it does help you out in ways that you wouldn't even think about. Cos before I'd have gone, "yeah right, okay, just another thing to not do", and then beat myself up some more about it!

(I) Yeah?

(P4) And then be back on the floor again! But touchwood, she says, it's...I've been teaching my daughters as well, so

(I) Oh okay, so you're teaching your daughters as well?

(P4) Yeah, so that's kinda going on as well at the moment, so...I think sometimes you just need to be shown a couple of times, and then it depends on how your head is. Maybe you can carry it through. Just think its not long enough! [laughs]

(I) Well actually thats a really good thing

(P4) [Getting a little tearful] Know what I mean?

(I) Hmmm, to know, uhm

(P4) I have certain days of the week that I have to do stuff, like Wednesday's today and I'm here, tomorrow I meet my counsellor and I'm with her on the Thursday. So, you know, it's like part of my routine at the moment, so I don't know what I'm gonna do next Wednesday! I wont see Joanne either!

(I) Ahh, well that is a downside, definitely

(P4) I know

(I) Ok, thank you, thats really....How about you P5, what, what do you think you've learnt from...

(P5) Make friends as well

Comment [NEC21]: Continued talk about engaging in self-criticism, situations/events in which this would occur or in response to [CODE 5]; implicitly & explicitly pointing out negative impact of self-criticism on their life

Comment [NEC22]: Talking about how the ability to take in/receive (and feeling more able to accept?) compassion from others has increased [CODE 10]; is helpful and beneficial in positive change; how this has helped them feel less alone in their difficulties [CODE 12]

Comment [NEC23]: Talking about doubts/initial reluctance (blocks & resistances) to the practice [CODE 17]; how fears & self-criticism get in the way of trying something new; implying that a sense of safeness & courage was important in order to try something new???

Comment [NEC24]: Talking about teaching what they have learnt (e.g. experiential practices) to others [CODE 28]

Comment [NEC25]: Talking about the importance of being shown how to be compassionate to yourself first (i.e. modelled & internalised) before one can do it themselves [CODE 18]

Comment [NEC26]: Talking about how the group was too short [CODE 20]; could do with more sessions, time to learn & generalise to day-to-day life???

Comment [NEC27]: Talking about the importance and helpfulness of routine [CODE 21]; losses & worries as a result of the group ending???

Comment [NEC28]: Talking about the social/relational benefits of attending the group, such as friendships with other group members [CODE 22]

(I) So making friends? Yeah? Yeah, that's an important thing, yeah. Anything else you can think of that you've learnt? You said a few things earlier on...

(P5) Me mindfulness

(I) Your mindfulness?

(P5) Uh-hmm

(I) Okay

(P5) Xxxxxx Xxxxx [another psychologist] got me to do that

(I) Ahhh right, so you've done

(P5) She's my psychologist

(I) Yeah I know Xxxxxx, yeah, yeah. So you, so you'd done some with Xxxxxx, some mindfulness already?

(P5) Yeah

(I) And you'd done some in this group?

(P5) I did it at home as well

(I) So what, so what do you do?

(P5) I close me eyes, and do the breathing exercises, and I find it helps me with me walk cos I used to have panic attacks when I went out, but it don't happen so much now

(I) Okay

(P5) And I find breathing helps me

(I) So was that part of...did that...did you do that from this group as well? Did you learn about that here?

(P5) Yeah, yeah

(I) Right, okay. Okay, is this...so you do your breathing. Are there, have you got like a favourite one that you, with your mindfulness, that you do?

(P5) Not particularly, no

(I) No? [brief pause approx. 3 seconds] Okay, so what sort of time of day do you tend to use it then?

(P5) Morning, noon and night! [Laughs]

(I) Oh right, yeah, wow. Okay, okay, thank you, that's great. How about you P6, what do you think you've, you might have said a bit earlier on but, I wonder if you could tell me again what, what you think you've learnt from coming here?

Comment [NEC29]: Talking about mindfulness (non-specifically described) as a learnt & helpful practice [CODE 23]; talking about engaging in mindfulness practice at home (i.e. home/personal practice)

Comment [NEC30]: Talking about how mindful soothing breathing ('Calm Breathing') was memorable and helpful, and being able to describe it positive emotional/neurophysiological & behavioural effects [CODE 24]

Comment [NEC31]: Talking about how they have no preference for a particular practice [CODE 27] → contradicting self from earlier?!?

Comment [NEC32]: Talking about engaging in practices outside of group in other contexts, and frequency of practices [CODE 25]

General Appendix 2. THEMATIC ANALYSIS – MASTER CODING TABLE

Code	Transcript, page no., line(s)	Quote (participant number)	Additional Comments/Observations
1. Wanting to feel better about self	2, p.1, line 3	(P5) To make me feel better about myself	Reflects reasons and motivations for coming, what they would like to change and/or be different
	2, p.1, line 11	(P4) Yeah, I think the same as well.	
	2, p.2-3, line 58-65	(P6) Uh huh. I got, I got to the stage where I got fed, fed up of lock, lock, locking me in my room, not socialising, wanted to be a calmer person, so so I went (I) Okay. So the idea that you wanted to be a calmer person? (P6) Yeah (I) Okay (P6) I thought its not help, helping locking myself in my room cos you wouldn't, wouldn't want a life at the end(?inaudible? → see 3 mins 25 secs), because it was getting to the stage where all of my friends were getting	

		upset	
2. Wanting to change how they feel about and relate to others	2, p.1, lines 5-10	(P5) And other people as well (I) Yeah. "To make you feel better about yourself", and and... (P5) Other people (I) And to feel better about other people? (P5) Yeah (I) Ok. Ok. Thank you	Reflects reasons and motivations for coming, what they would like to change and/or be different
3. Wanting to deal better with life events/problems	1, p.2, lines 49-51 1, p.2, lines 54-57 1, p.2-3, lines 61-71	(P1) And it might help you because I've got issues, like...I've just recently lost Dad, so... (I) Right...[writes on flipchart] So your sister thought it might be helpful for you? (P1) Yeah. (P3) Ummmmm...problems in life...family. (I) Yeah? [writes on flipchart] 'Problems in my life'. So, did you think if you came to the group it might help you to cope with those? (P3) Yeah.	Reflects reasons and motivations for coming, what they would like to change and/or be different

		(P2) Urrmm, my brother and sister. (I) Okay. [writes on flipchart] What did they say to you? (P2) It's just like, like, I can't like see them anymore, so I thought to come here like to help me out like kinda cope sort of thing. (I) Okay. So again it was about coping (P2) Yeah. (I) With the things that were quite difficult. (P2) Yeah. (I) [Pause and silence whilst writes on flipchart for approx. 5 seconds] Would you say, coping with not seeing them? (P2) Yeah, like, with not seeing them, like...yeah.	
4. Wanting to be less self-critical	2, p.1, lines 11-12 2, p.3, lines 84-85	(P4) It's like, you've been, I've been beating myself up for such a long time, and even the last, forever... (P4) Instead of being the one	Realisations around how long they have been self-critical, and the negative impact this has had; ; also reflect reasons and motivations for coming, and what they would like to change/be different

		that (brief pause)...you're beating yourself up, cos the way I was, I was proper (brief pause)...I was horrible to me self, and...	
5. Talking about engaging in self-criticism/self-blame, and negative impact of shame & self-criticism	2, p.1, lines 11-14 2, p.3-4, lines 91-98	(P4) It's like, you've been, I've been beating myself up for such a long time, and even the last, forever...I wanted, I didn't...although I knew people felt the same way I did, anxious and scared and depressed and fed up, I always used to beat myself up to the point where I didn't wanna be here anymore. (P4) I used to get really anxious and really really, if I was in a meeting anywhere I'd be effin' and jeffin' at them, cos I wouldn't understand what they were saying, and then all of a sudden they're going "naair nair nair nair nair [finger wagging, pointing], don't do this, don't do that" and I'd be like "Argh, argh!" And	Realisations around how shame and self-criticism has negatively impacted on their lives – mood, sense of self etc. Common humanity around shame/self-criticism?

	2, p.7, lines 205-208 2, p.14, lines 431-435	because I, I didn't understand what was going on in my own head, never mind what they were saying, I was kicking off (I) Right (P4) And getting really angry with them, and swearing and screaming at them. And then, coming out of that meeting and beating myself up again. So, it was like, I was on the floor before you knew it. (P5) I used to blame me self because me mom died six years ago, and I blamed me self for that as well. Think it's my fault you know, all the worry about you know and that (I) Uhm, yeah, so its something that people do a lot isn't it? (P5) Uhhmmm [nodding] (P4) ...and I've got a tendency to...even if I'm okay for a while, I've got a tendency to	

	2, p.15, line 448	beat myself up anyway...cos I'd rather do it than let someone else do it, and I think (I) So you've got a tendency there already, yeah? (P4) Yeah, the, I think it's... (P4) ...I've always been the same: beatin' me self up, doin' it again, do it again, do it again, do it again	
6. Anxious/reluctant/ambivalent around going to group	2, p.1, lines 16-17	(P4) And this course was, erm, suggested to me, I first thought "naaah, not another one!" Cos I've been on courses before	Reflects FBRs to going to the group
7. Negative previous experiences of attending other groups	2, p.1, lines 18-25	(I) Oh, why you've been on courses before? (P4) Not THIS one! I've been on erm confidence courses before (I) Yeah (P4) And that didn't go down very well, cos the people that were in the course actually lived in the same area that I did, and went to the same, hung around the same	Reflects FBRs to going to the group

		neighbourhood that I did (I) Oh okay (P4) Which wasn't very good, because what everyone said in the group kind of over-spilled into my personal life, which wasn't good either.	
8. Encouragement from others to go to the group	2, p.1, lines 29-30 2, p.2, lines 38-41 2, p.3, lines 68-69 1, p.2, lines 40-51	(P4) Um, and when it was suggested to me again, uh had a word with my friend and she said, "well you know, try it, you don't know what will happen until you try it." And to be honest I'm glad I did (I) ...So it's a bit like, people had said "why don't you give it a go?", and then you gave it a go, and (P4) I'm glad I did (I) And you're glad you did. (P6) And, and all my friends suggested that I should go to group because they, they said they were getting a bit fed up of me being negative	Reflects reasons and motivations for going to the group

		(I) Can you have a think back to the very first time that you found out about the group, what made you want to come? (P1) My sister. (I) Okay...so, your sister...I'm gonna, if I sit here is that ok for everybody? (P2) Yeah. (I) Yeah? So, your sister [writing down answer on flipchart for approx. 5 seconds]. And, what did she say to you? (P1) Ooh, she just...knew Neil and Jonathan, and said that there's a group starting... (I) Okay. (P1) And it might help you because I've got issues, like...I've just recently lost Dad, so... (I) Right...[writes on flipchart] So your sister thought it might be helpful for you? (P1) Yeah.	
9. Talk about everything being	1, p.4, lines 93-101	(P2) Everything really, hum,	General tendency to describe

helpful (non-specific beneficial effects of attending the group)	1, p.5, lines 128-130 1, p.5, lines 138-139 1, p.11, lines 295-298	(I) Hey? (P2) everything really (F1) Everything? (P2) Yeah. (I) Everything's a really big word. Can you tell me a bit more about that? What does everything mean? (P2) Like, how to like cope with things and stuff like that. (I) Uh huh [writes on flipchart] "How to cope with things"...and you said "stuff like that". What, what's that mean? (P2) Like, like when you like breathing and things like that, and.. (I) Yeah? So what would you say you learnt from the group? (P3) Quite a lot. (I) Quite a lot? What sort of stuff? (P3) Ummmm (pause for approx 8 seconds whilst	derived emotional benefits, without being able to identify specifics (e.g. how it has helped, what has changed)

		formulating an answer), ummmm, there is quite a lot but I cant think of one word more.	
	2, p.2, lines 32	(I) ...Okay. So, what was the most helpful part of the group and why? What do we think was most helpful?	
	2, p.12, lines 367	(P3) Um, everything about it. (P2) Yeah, everything really.	
	2, p.19, line 577	(P4) Because it has, it has helped me quite a lot...	
	2, p.21, line 619-620	(P4) I think everything, in, in its own way as helped us all in a different way	
		(P6) I'm, I'm finding it really positive now thanks to this	
	1, p.15, line 410-415	(P4) And I, I would literally do it all over again, because its, it has helped so much, but...you know, you cant cover everything you've had happen or done in six weeks	

	2, p.17, lines 487-496	(I) What d'ya think? What was the least helpful part? [Pause for approx 10 seconds] (P2) Can't think of any! [laughs] (I) Was there anything when you thought, "oh why are we doing this? This is awful, I really don't wanna do it!" or "I don't see how this is going to help me" or "I wish they'd done this"? Anything like that? (Brief pause) (P2) No, cant think of any. (I) ...Anything else you can think of about how you found them? (P2) Mmm, helpful. (I) Helpful? Brilliant, that's a good start. [F1 then provides a prompt/reminder of some of the practices/exercises undertaken in group] So, how were all of those? (P2) Umm...good. (I) What was good about them?	

		(P2) Ummm, everything really. Like, help me type of thing, stuff like that (I) Uh-huh? So, "everything was good, it helped you." (P2) Yeah.	
10. Increased confidence to express self	1, p.7, lines 178-182 2, p.2, lines 32-37 2, p.9, lines 266-267	(P2) Like, speaking about my feelings and that (I) Uh hum? So, is that something you didn't do very much before? (P2) Not much, no. (I) No. Would you feel more confident in doing that now? (P2) Yeah. (P4) ...I mean, if you'd have been here day one like Xxx said (I) Yeah (P4) I was, I never shut up! And then, I...I didn't think for one minute that I'd say anything (I) Okay (P4) But I didn't shut up! (P4) That was everything. Um, and I suppose the good I	Reflects emotional changes – (positive) change in sense of self Changes in both *inter* & *intra*personal relating? Increase in social safeness (feeling safer and more connected to others)? Reduced shame?

	2, p.18-19, lines 549-561	got out of that one was...I, I opened up here. I didn't think I would but I did. (P6) ...I said I forgot that bit Xxxxx, I upset my mate, I said I didn't mean to upset you. I pushed my mate Xxxxx a bit though, I said, I, that's why I thought I'd upset my mate cos I forced him, I forced you to do it (P4) Yeah, but I spose in that respect, when he did it, did he chill out a little bit? (P6) Yeah, ch chill him out, chilled him out (P4) Exactly (P6) I said I'm like a brother to you Xxxxx (P4) Yeah, so so, where, you didn't wanna upset him, he's he's then taken that onboard and he's been alright with you, aint he? (P5) He, he's alright when I reminded (P4) Exactly (P6) I reminded him he's got	

		me (P4) Yeah	
11. Being and feeling less negative (about self and others)	2, p.3, lines 71-73	(P6) So, so I'm not that negative like I used to be (I) So other people had noticed (P6) Yeah	Changes in sense of self, self-to-self relating, positive emotional shifts
12. Feeling less alone with one's difficulties/suffering	1, p.7, lines 195-201 2, p.3, lines 80-81 2, p.4, lines 100-102	(P3) And being in like the same boat and all that (P2) Yeah (I) Ahhh, ok, so you learnt that everybody's in the same boat and (P2) Yeah. (P3) Trying to get through life (I) Yeah? (P2) And we're not alone. (P4) Its like, you're not, you're not on your own. You know, there are other people that are going through the same thing... (P4) ...I have managed [brief pause approx. 3 seconds]...I'd say [chuckles], erm, I've managed to realise that, that	Common humanity – de-shaming, increase in sense of connectedness? Positive emotional changes/shifts?

		I'm not on my own. I have got people who, who are gonna be there to support me and help me change, to be the person I wanna be, cos I've I've always been nice, but I just don't, I'm just not nice to myself	
13. More able to be kind to self and others	2, p.3, lines 81-84 2, p.12, lines 347-348 1, p.10, lines 272-290	(P4) ...and you know you can...you can find it in, in yourself to be nice to yourself, to be nice to other people (I) Uh huh (P4) Instead of being the one that (brief pause)...you're beating yourself up (P6) The, the being kind, kinder to yourself ones help, cos cos I don't think much that I'm a weak link anymore much (I) Sounds like you've learnt loads, really good, brill! And then he's also put being kind and caring rather than mean to yourself	Changes in self-to-self and self-to-other relating (increased self and other compassion); development of courage?

	1, p.21-22, lines 602-617	(P3) Yeah. (P1) Definitely! (P2) Definite. (I) Definitely? Is that a big double tick on here? (P2) Yeah he he (P1) Yes! (P2) Definitely. (I) Are you all managing to do that? (P2) Getting there, but yeah ha ha! (I) Getting there...getting there's good cos it means you're on the way to doing it. (P2) Yeah. (I) Which is good. What about you? (P3) Same really! (I) Same, getting there? (P3) Yep. (I) What about you, P1? (P1) Getting there. (I) ...So do you think the group has changed the way you feel about, talk to, and treat yourself? (P2) Hum...yeah, found it	

		hard a little bit, but getting there though (I) Uh huh? So, you found it, found it hard a little bit, but you're getting there? (P2) Yeah (I) When did you find it most hard? (P2) Umm...my whole life really (I) So your whole life you've found it hard? (P2) Yeah (I) And then when you started coming to the group, did you find that it was harder at first? (P2) At first it was a bit hard, but the easier it got, bit at first its hard, at first (I) Yeah? So compared to when you started the first session, do you feel like its a bit easier to put it all into practice? (P2) Yeah, like putting together a jigsaw and that! But with practice it gets easier	

		(I) Yeah, that's good. So hopefully with practice, it might still get a bit easier? (P2) Yeah	
14. Talking about reasons for being self-critical	2, p.3, lines 87-90	(P4) Like, like I said to Neil, I would rather me be nasty to myself and beat myself up in the head, than let someone else do it (I) Like, you're getting in there first?!? Yeah, yeah?!? (P4) Yeah...	Insight into functions of self-criticism (realising where it developed, why they do it, fears behind dropping/changing it)
15. Talk about being more able to take in compassion (kindness, support, encouragement) *from* others	2, p.4, lines 99-102 2, p.12, lines 348-354	(P4) ...And, through some good help and some good people, I have managed [brief pause approx. 3 seconds]...I'd say [chuckles], erm, I've managed to realise that, that I'm not on my own. I have got people who, who are gonna be there to support me and help me change, to be the person I wanna be... (P6) ...cos my mate Xxxxx was getting a little bit fed up that I was, he said "you're not, you're a nice person".	Changes in other-to-self relating (affiliation) → interpersonal, increased social safeness?

		(I) Yeah (P6) Cos Xxxxx, he doesn't tell me it, and then I don't always think that (I) Okay (P6) So I said to Xxxxx "don't, don't, don't be silly", but then I thought "wait a minute he's right, I am a nice person" because I like helping people, and I had a second thought about	
16. Talk about being able to be kind/nice to others, but not the self	2, p.4, lines 102	(P4) ...I've always been nice, but I just don't, I'm just not nice to myself	Recognising differences in the *flow* of compassion; reflective of submissive niceness?
17. Blocks and resistances to practices	2, p.4, lines 104-110	(P4) But this group, it...it showed me that, even although when I first did the breathing I thought "What is he on?!?" (I) Yeah! Ha ha! (P4) Thinking that, ha ha, you know, "This is daft!" But once I, once I let myself do it, it was kind of relaxing, and it does, it does help you out in ways that you wouldn't even think about. Cos before I'd have gone, "yeah right, okay,	Representative of common fears/blocks/resistances (FBRs) to compassion practice(s)

	2, p.9, lines 262-266	just another thing to not do", and then beat myself up some more about it! (P4) That's the one that I found really difficult, wasn't it? (S1) Yeah (P4) That's the one I found really really difficult (I) So you found the (three) circles really difficult? (P4) Yeah, cos everything in my head was in the red	
	1, p.18, lines 505-510	(I) So that's the threat bit isn't it? (P4) That was everything... (I) Did you find them helpful in the session, but not outside? Or did you... (P1) Mmm (nodding) (I) Yeah? Cos I know you said you didn't practice them so much outside the session... (P1) No	
	1, p.18, lines 515-521	(I) But when you were here in the moment, you thought that it was really helpful?	

	1, p.21, lines 590-600	(P1) Yeah. (I) Okay. So here's a question we've talked about a bit. How often did you use the exercises or practices outside of the session? (P1) I didn't (I) No? Was there anything that stopped you from using them? (P1) No (I) No? Did you just not want to? (P1) [nods] (I) Do you reckon there are any ways that you might be able to start incorporating it into your everyday life? (P1) [Shakes head] (I) No? Any reminders or anything? (P1) [Shakes head] (I) No? Do you not feel like you want to? (P1) [Nods] (I) Is that a nod that you don't feel like you want to?	

		(P1) [Nods] (I) But when you came to the group, it was good? (P1) Yeah	
18. Becoming less self-critical	2, p.4, lines 108-112 2, p.9, lines 269-271 1, p.8-9, lines 236-242	(P4) ...Cos before I'd have gone, "yeah right, okay, just another thing to not do", and then beat myself up some more about it! (I) Yeah? (P4) And then be back on the floor again! But touchwood... (P4) ...my dad has actually said it was, its basically his and my mum's fault the way that I've turned out. And it wasn't, okay I was a brat, but it wasn't, you know, everything that happened after, it wasn't my fault. (I) Do you remember "not your fault" as well? (P1) Yes. (P3) Yeah. P2) Yeah. (I) Yeah? Was that something that was helpful for you? (P3) Yep.	Realisation of 'not your fault' concept & focus, and feeling it emotionally (de-shaming)

		(P2) Yeah...yeah. (I) Was it for you P1? (P1) Yes.	
19. Talk about the importance of being shown how to, and practicing, being kind to yourself	2, p.4, lines 115-116 2, p.14, lines 435-436 2, p.15, lines 438-443	(P4) Yeah, so that's kinda going on as well at the moment, so...I think sometimes you just need to be shown a couple of times, and then it depends on how your head is. Maybe you can carry it through. (P4) ...the being kinder part was nice because somebody else saw that in in you, that you know is already there but you just can't access it (P4) See, when S3 said to me the other day, "just take it easy, just chill", and I was like "What?" he he [laughs]. And he was like, then Neil was like, now say it to her again, slowly and calmly, and in a nice voice (S3) Yeah (P4) And I was like, when he said it again, I was like "ahhh,	Reflects challenges in developing self-compassion, but importance of *practice* and being encouraged-supported to do so (overcoming SBR, getting used to, feeling more reassured by – emotional benefits and changes)

	1, p.21-22, lines 602-617	he sounds like me dad!" And it, it just chilled me out a little bit (I) ...So do you think the group has changed the way you feel about, talk to, and treat yourself? (P2) Hum...yeah, found it hard a little bit, but getting there though (I) Uh huh? So, you found it, found it hard a little bit, but you're getting there? (P2) Yeah (I) When did you find it most hard? (P2) Umm...my whole life really (I) So your whole life you've found it hard? (P2) Yeah (I) And then when you started coming to the group, did you find that it was harder at first? (P2) At first it was a bit hard, but the easier it got, bit at first its hard, at first	

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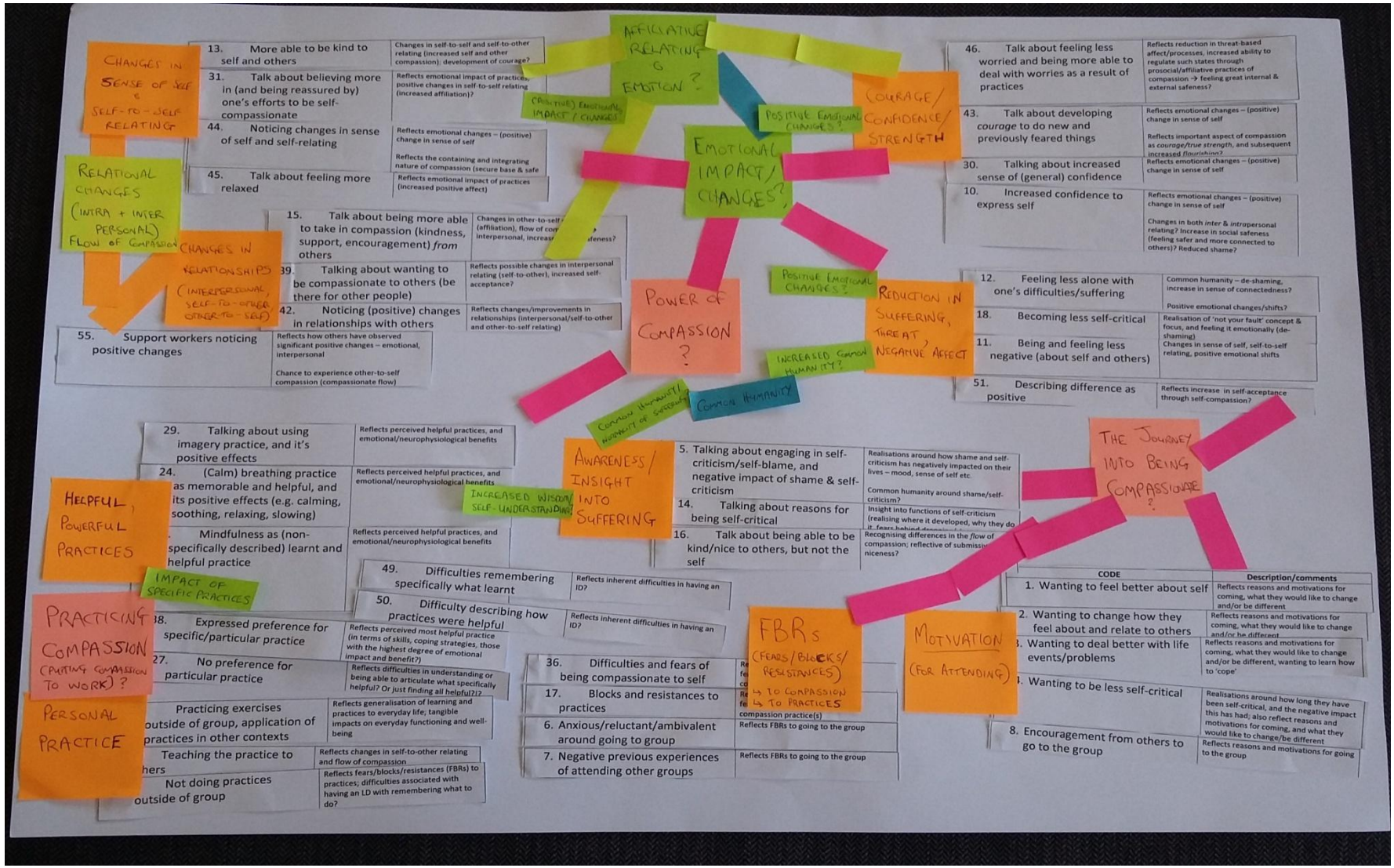
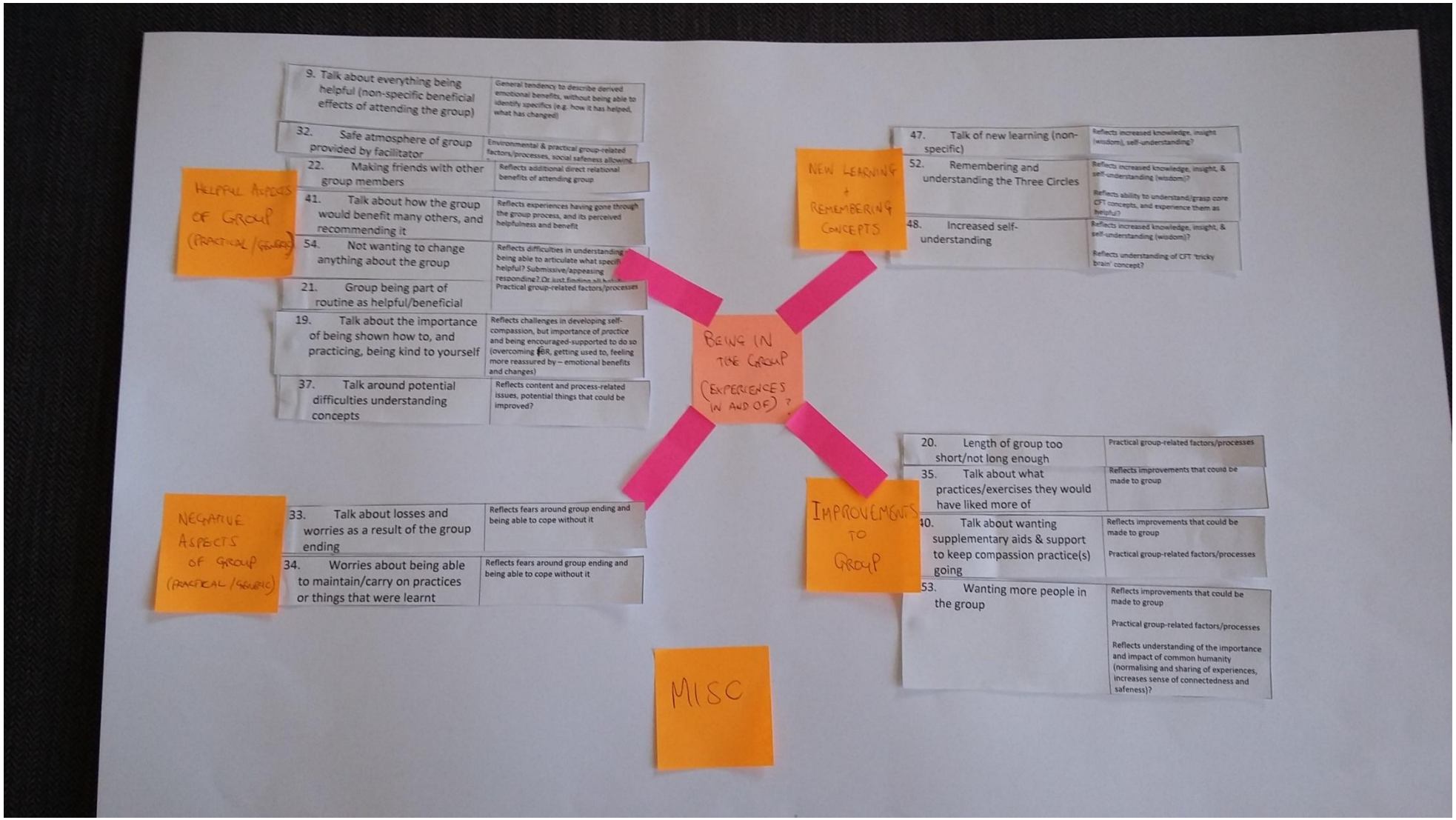
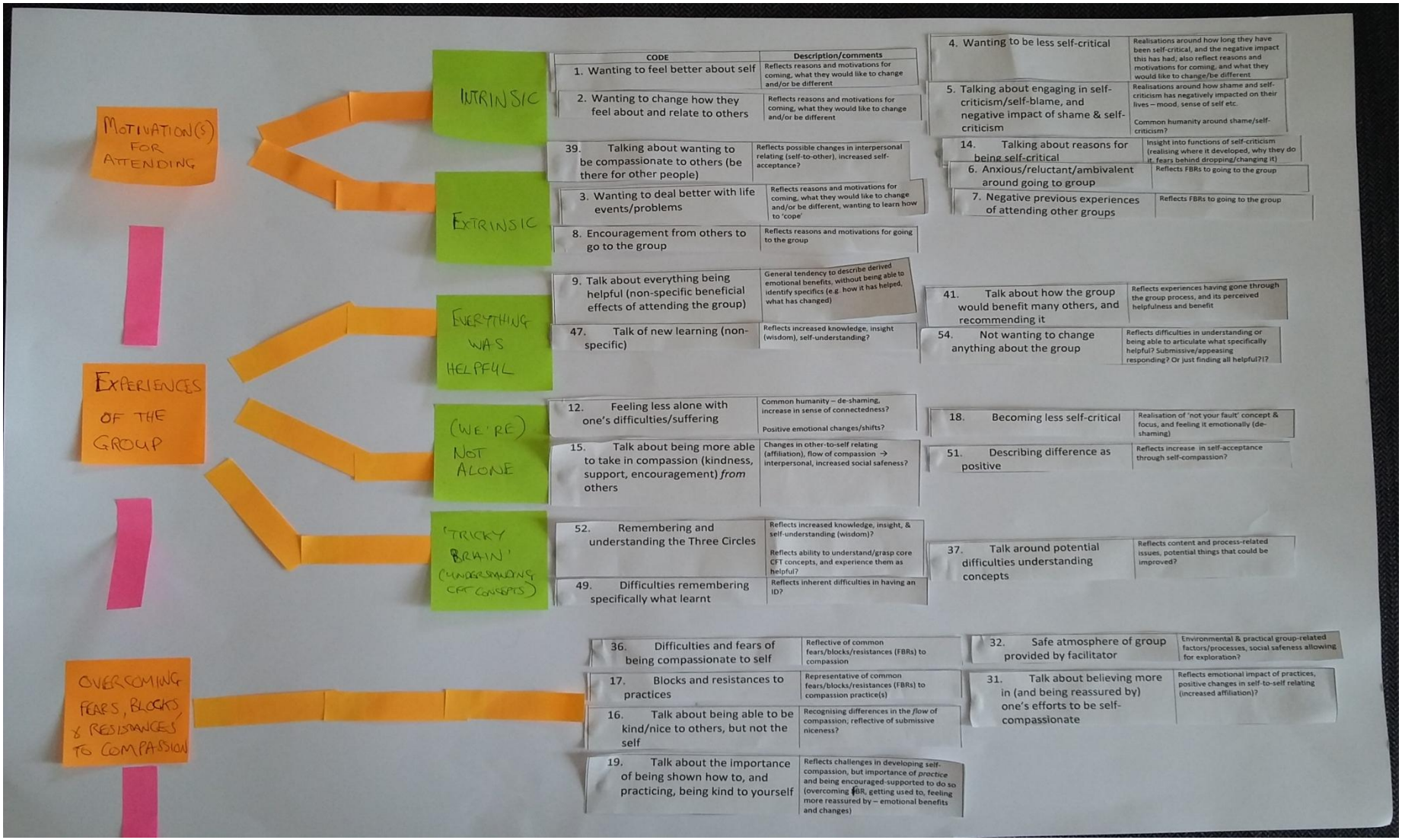
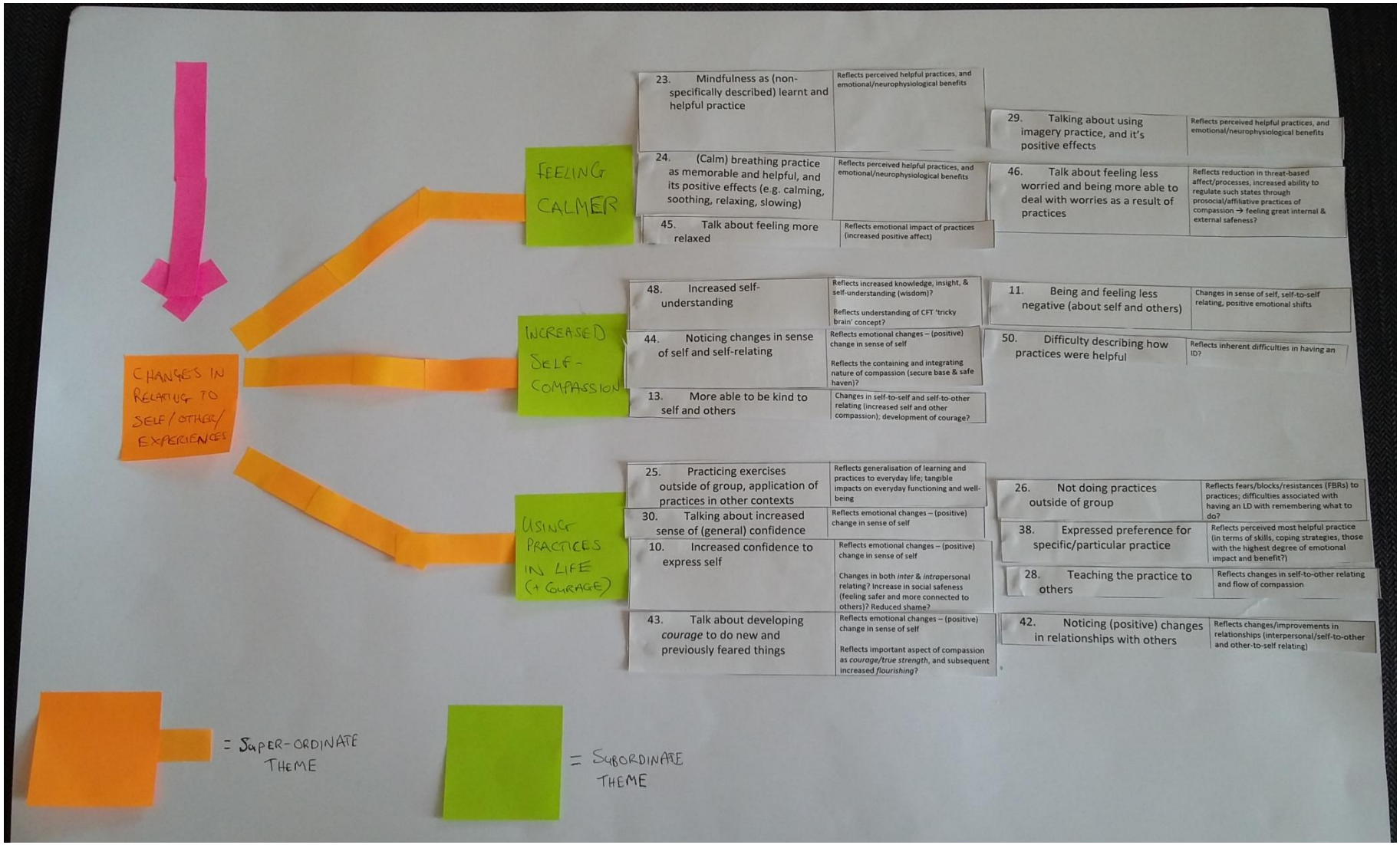
General Appendix 3: Example Thematic Map (identification, generation, sorting of and relationship between Themes)




BEING IN THE GROUP (EXPERIENCES IN AND OF)?
HELPFUL ASPECTS OF GROUP (PRACTICAL / GENERIC)
9. Talk about everything being helpful (non-specific beneficial effects of attending the group)
General tendency to describe derived emotional benefits, without being able to identify specifics (e.g. how it has helped, what has changed)
32. Safe atmosphere of group provided by facilitator
Environmental & practical group-related factors/processes, social safeness allowing
22. Making friends with other group members
Reflects additional direct relational benefits of attending group
41. Talk about how the group would benefit many others, and recommending it
Reflects experiences having gone through the group process, and its perceived helpfulness and benefit
54. Not wanting to change anything about the group
Reflects difficulties in understanding / being able to articulate what specifically helpful? Submissive/appeasing responding? Or just finding all
21. Group being part of routine as helpful/beneficial
Practical group-related factors/processes
19. Talk about the importance of being shown how to, and practicing, being kind to yourself
Reflects challenges in developing self-compassion, but importance of practice and being encouraged-supported to do so (overcoming FBR, getting used to, feeling more reassured by – emotional benefits and changes)
37. Talk around potential difficulties understanding concepts
Reflects content and process-related issues, potential things that could be improved?
NEW LEARNING + REMEMBERING CONCEPTS
47. Talk of new learning (non-specific)
Reflects increased knowledge, insight (wisdom), self-understanding?
52. Remembering and understanding the Three Circles
Reflects increased knowledge, insight, & self-understanding (wisdom)?
Reflects ability to understand/grasp core CFT concepts, and experience them as helpful?
48. Increased self-understanding
Reflects increased knowledge, insight, & self-understanding (wisdom)?
Reflects understanding of CFT 'tricky brain' concept?
IMPROVEMENTS TO GROUP
20. Length of group too short/not long enough
Practical group-related factors/processes
35. Talk about what practices/exercises they would have liked more of
Reflects improvements that could be made to group
40. Talk about wanting supplementary aids & support to keep compassion practice(s) going
Reflects improvements that could be made to group
Practical group-related factors/processes
53. Wanting more people in the group
Reflects improvements that could be made to group
Practical group-related factors/processes
Reflects understanding of the importance and impact of common humanity (normalising and sharing of experiences, increases sense of connectedness and safeness)?
NEGATIVE ASPECTS OF GROUP (PRACTICAL / GENERIC)
33. Talk about losses and worries as a result of the group ending
Reflects fears around group ending and being able to cope without it
34. Worries about being able to maintain/carry on practices or things that were learnt
Reflects fears around group ending and being able to cope without it
MISC

General Appendix 4: Final Thematic Map




CHANGES IN RELATING TO SELF / OTHER / EXPERIENCES
FEELING CALMER
INCREASED SELF-COMPASSION
USING PRACTICES IN LIFE (+ COURAGE)
23. Mindfulness as (non-specifically described) learnt and helpful practice
Reflects perceived helpful practices, and emotional/neurophysiological benefits
24. (Calm) breathing practice as memorable and helpful, and its positive effects (e.g. calming, soothing, relaxing, slowing)
Reflects perceived helpful practices, and emotional/neurophysiological benefits
45. Talk about feeling more relaxed
Reflects emotional impact of practices (increased positive affect)
29. Talking about using imagery practice, and it's positive effects
Reflects perceived helpful practices, and emotional/neurophysiological benefits
46. Talk about feeling less worried and being more able to deal with worries as a result of practices
Reflects reduction in threat-based affect/processes, increased ability to regulate such states through prosocial/affiliative practices of compassion → feeling great internal & external safeness?
48. Increased self-understanding
Reflects increased knowledge, insight, & self-understanding (wisdom)?
Reflects understanding of CFT 'tricky brain' concept?
44. Noticing changes in sense of self and self-relating
Reflects emotional changes – (positive) change in sense of self
Reflects the containing and integrating nature of compassion (secure base & safe haven)?
13. More able to be kind to self and others
Changes in self-to-self and self-to-other relating (increased self and other compassion); development of courage?
11. Being and feeling less negative (about self and others)
Changes in sense of self, self-to-self relating, positive emotional shifts
50. Difficulty describing how practices were helpful
Reflects inherent difficulties in having an ID?
25. Practicing exercises outside of group, application of practices in other contexts
Reflects generalisation of learning and practices to everyday life; tangible impacts on everyday functioning and well-being
30. Talking about increased sense of (general) confidence
Reflects emotional changes – (positive) change in sense of self
10. Increased confidence to express self
Reflects emotional changes – (positive) change in sense of self
Changes in both inter & intrapersonal relating? Increase in social safeness (feeling safer and more connected to others)? Reduced shame?
43. Talk about developing courage to do new and previously feared things
Reflects emotional changes – (positive) change in sense of self
Reflects important aspect of compassion as courage/true strength, and subsequent increased flourishing?
26. Not doing practices outside of group
Reflects fears/blocks/resistances (FBRs) to practices; difficulties associated with having an LD with remembering what to do?
38. Expressed preference for specific/particular practice
Reflects perceived most helpful practice (in terms of skills, coping strategies, those with the highest degree of emotional impact and benefit?)
28. Teaching the practice to others
Reflects changes in self-to-other relating and flow of compassion
42. Noticing (positive) changes in relationships with others
Reflects changes/improvements in relationships (interpersonal/self-to-other and other-to-self relating)
= SUPER-ORDINATE THEME
= SUBORDINATE THEME

WORD COUND STATEMENT

Thesis Component	**Word Count**
Section/Title pages	80
Thesis Abstract	300
Literature Review	7,020
Empirical Paper	7,052
Contributions to Theory and Clinical Practice	4,959
Word count excluding tables, figures, reference lists and appendices	**19,411**

Figures, Tables, Reference Lists, and General Appendices

Literature Review Acknowledgements & Declarations	75
Literature Review References	2,147
Literature Review Appendix 1 (Table)	1,327
Literature Review Appendix 2 (Figures)	227
Empirical Paper Acknowledgements & Declarations	119
Empirical Paper References	1,593
Empirical Paper Appendix 1 (Tables)	776

Empirical Paper Appendix 2 (Figures)	86
Contributions to Theory and Clinical Practice References	2,644
Extract from focus group transcript (General Appendix 1)	2,424
Extract from master coding table (General Appendix 2)	3,734
Initial thematic map(s)	14
Final thematic map	20
Appendices including figures, tables and reference lists,	
excluding ethics appendix	**15,186**

Total Word Count	**34,597**