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# Understanding perinatal mental health peer support in the third sector using critical realism

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A thesis submitted to City, University of London for the Degree of Doctor of Philosophy in the School of Health Sciences

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# **Declaration**

I, Jenny McLeish, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.



# Abstract

#### Background

Mental health difficulties are common in the perinatal period. Peer support has been proposed as a way to improve emotional wellbeing, but the evidence base for third sector programmes is undeveloped. The overall aim of this research was to deepen understanding of what it is about perinatal mental health peer support in the third sector that works, for whom, in what circumstances, in what respects, and why.

#### Setting

Parents in Mind, a pilot third sector programme offering one-to-one and group perinatal peer support from trained volunteers at three sites in England.

#### Methods

A critical realist, mixed methods, theory-based process evaluation, supported by a realist review. An initial theory of change was used to guide the evaluation. Quantitative programme data and data from mothers' self-report questionnaires were analysed with descriptive and inferential statistics. Qualitative interviews with 20 supported mothers, 27 volunteers, six staff and three trainers were analysed using realist principles and some techniques from Grounded Theory. Retroduction was used to explore configurations of contexts, mechanisms and outcomes and construct a final theory of change.

#### Results

182 mothers received peer support from 77 volunteers. Three-quarters of mothers were White British, nearly half were socio-economically disadvantaged, and three-quarters had a previous history of mental health difficulties. There were many contextual differences between the three sites, and local and national adaptations were made. The final theory of change included 16 programme theories linking contextual factors to mothers' individual *choices to use peer support*, based on a mother's beliefs about the utility of talking to others and to peers specifically; social expectations; her relationship with health and social care professionals and mental health services;

perceived practical benefits; and ability to overcome barriers to access. A further 16 programme theories explained *positive impact on mothers*, including through feeling understood and accepted, normalisation, social comparison and information sharing; and 12 theories explained *negative impact on mothers*, where key peer support mechanisms were absent or through negative social comparison. Eight programme theories explained the *positive impact on volunteers*, based on their own experience of peer support and insight into mental health during training, gaining skills and confidence, and satisfaction at helping others; and seven theories explained the *negative impact on volunteers*, because of feeling emotionally 'triggered', stressful social dynamics between volunteers, and distress if they did not feel their support was helping mothers. Individual mothers and volunteers were affected in different ways, depending on their individual backgrounds, personalities, social situations, resources, experiences, beliefs, and needs. Parents in Mind had robust processes to keep volunteers and mothers emotionally safe, and all participants considered the benefits of peer support to greatly outweigh the risks.

**Conclusions:** The Parents in Mind peer support model is safe and capable of enabling positive change for both mothers and volunteers through multiple contextualised pathways. Outcome measures should recognise that mothers (and volunteers) benefit from peer support in a range of ways, and programmes should be aware of the potential for negative effects in order to mitigate these. Programmes should work with local communities to understand what they want so that the peer support offer is adapted flexibly to their needs.

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BDI	Beck Depression Inventory
С	Context
C-M-0	Context-mechanism-outcome
CBT	Cognitive Behavioural Therapy
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
EPDS	Edinburgh Postnatal Depression Scale
GAD-7	Generalized Anxiety Disorder 7 item scale
HADS	Hospital Anxiety and Depression Scale
IAPT	Improving Access to Psychological Therapies: NHS psychological therapies service
IPT	Interpersonal therapy
LPM	Local project manager
Μ	Mechanism
MBU	Mother and Baby Unit, a specialist in-patient facility
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
0	Outcome
OCD	Obsessive compulsive disorder
PHQ9	Patient Health Questionnaire 9 item scale
PSEI	Peer Support Evaluation Inventory
PTSD	Post-traumatic stress disorder
RAMESES	Realist And Meta-narrative Evidence Syntheses: Evolving Standards project
RCT	Randomised controlled trial
V	Volunteer (used after volunteers' pseudonyms)

# Abbreviations

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# **1** Introduction

#### **Chapter overview**

The topic of this thesis is community-based peer support for women with mental health difficulties during pregnancy and afterwards. This chapter provides an overview of the prevalence of mental health difficulties in the perinatal period and the policy response in England. It outlines peer support as an intervention for mental health, and the development of perinatal mental health peer support, identifying the limitations of the evidence. It introduces the Parents in Mind peer support programme which was the setting for this research. It describes the research aims and objectives and the structure of the thesis.

> "Sometimes in our lives we all have pain, we all have sorrow. But if we are wise, we know that there's always tomorrow. Lean on me when you're not strong, And I'll be your friend, I'll help you carry on For it won't be long Til I'm gonna need somebody to lean on."

Bill Withers, 'Lean on me', 1972

# 1.1 Poor mental health in the perinatal period

#### 1.1.1 **Definition of perinatal mental health difficulties**

Pregnancy and the year after birth are a critical time for mothers' mental health. Although there has historically been a focus on depression and the period after birth, pregnant women as well as new mothers can be affected a range of mental health difficulties such as depression, anxiety, eating disorders, drug and alcohol-use disorders, psychosis, bipolar disorder and schizophrenia (National Institute for Health and Care Excellence, 2014).

In England, mental health policy documents use the term 'postnatal' to refer mental health difficulties during first year after birth, and 'perinatal' to refer to pregnancy and the first year after birth (National Institute for Health and Care Excellence, 2014; NHS England et al., 2018). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has a narrower definition, classifying 'perinatal depression' as a major depressive disorder identified during pregnancy or within four weeks after birth (American Psychiatric Association, 2013). The wider definition of pregnancy and one year after birth is used in this thesis when discussing the literature on perinatal mental health, and an even wider definition of pregnancy and up to two years after birth is used when discussing

peer support, to mirror the criteria developed by the Parents in Mind programme, which was the setting for the primary research.

Like mental health difficulties occurring at other times, those occurring in the perinatal period vary in how much distress they cause. The National Institute for Health and Care Excellence (NICE) follows the DSM-5 approach to diagnosing depression according to both the number and severity of the symptoms, *and* the degree to which these affect the person's functioning (National Institute for Health and Care Excellence, 2021a). Clinically significant or 'major' depression is classified as severe, moderate or mild, and the term 'sub-threshold' is used to indicate that a person has at least two of the recognised symptoms of depression, but does not meet the other diagnostic criteria for clinically significant depression (National Institute for Health and Care Excellence, 2021a). A similar classification system is used for clinically significant generalised anxiety disorder (National Institute for Health and Care Excellence, 2021b).

Persistent sub-threshold symptoms may be highly distressing for the individual, and are associated with increased likelihood of developing clinically significant depression or anxiety (Rowe & Rapaport, 2006; Ruscio et al., 2007). NICE recognises the importance of addressing the needs of people with sub-threshold depression or anxiety, because these are each a spectrum with no natural discontinuity between symptoms that are above and below the diagnostic thresholds (National Collaborating Centre for Mental Health, 2010, 2011).

There are a variety of terms used to describe poor mental health or people who experience it, and some of these may be perceived as having negative connotations, while the acceptability of different terms changes over time (Mental Health Foundation, 2021). In this thesis, the term 'mental health difficulties' is used to refer inclusively to an experience of any aspect of poor mental health, of any degree of severity, that causes distress. It is intended as a neutral description and is not linked to diagnosis. The term 'mental illness' is used when discussing the associated stigma, and 'severe mental illness' is used to refer to psychosis, bipolar disorder and schizophrenia.

The term 'lived experience' is widely used within mental health literature, usually detached from its original philosophical connotations in phenomenology. In the context of peer support, it is often used simply to state that a person has personally experienced mental health difficulties; in the context of research, policy or service development, it may be used to acknowledge the particular way of knowing that comes from such experience (Byrne & Wykes, 2020; Gillard et al., 2017). In this thesis, 'lived experience' is primarily used in the former sense, reflecting its use by the research participants.

#### 1.1.2 Prevalence of clinically significant perinatal mental health difficulties

The most common clinically significant perinatal mental health difficulties are anxiety and depression, which may be diagnosed by a clinical interview, or identified as potential cases using screening questionnaires. Systematic reviews of global studies have found that the prevalence of a clinically diagnosed anxiety disorder is 15-20% during pregnancy and 10% postnatally (Dennis et al., 2017; Fawcett et al., 2019); the prevalence of clinically diagnosed depression is 21% during pregnancy (Yin et al., 2021) and 17-18% in the year after birth (Liu et al., 2021; Shorey et al., 2018; Wang et al., 2021); and the prevalence for clinically diagnosed co-morbidity is 9.5% during pregnancy, and 4.2% postnatally (Falah-Hassani et al., 2017). Estimating prevalence is complicated by the research being based on study populations that are not necessarily representative of ethnic diversity, and often excluding women with pre-existing mental health difficulties (Gavin et al., 2005; Woody et al., 2017). There may also be a substantial gap between prevalence and the identification of perinatal mental health difficulties in clinical practice - it has been estimated that 60% of cases of perinatal depression are undiagnosed (Gavin et al., 2015). Perinatal mental health difficulties may resolve spontaneously - evidence from the control groups in randomised controlled trials shows that 25-40% of women with postnatal depression recover without intervention (Dennis et al., 2012).

There is a strong continuity of mental health problems before and during the perinatal period. For example, a sequential case series of 10,000 women in the USA found that for the majority of mothers diagnosed with postnatal depression, this episode began during pregnancy (33.4%) or preexisted before pregnancy (26.5%) (Wisner et al., 2013). Women who have a baby may also be affected by a pre-existing severe mental illness such as bipolar disorder, or experience a new episode of severe mental illness soon after birth (postpartum psychosis) (Jones et al., 2014b). Approximately 1-2 in 1000 new mothers are admitted to a psychiatric hospital as a result of an episode of existing or new severe mental illness (Jones et al., 2014b). The prevalence of post-traumatic stress disorder related to birth is 4% (Yildiz et al., 2016).

#### 1.1.3 **Prevalence of lower level anxiety, depression and stress**

There are also many mothers who have symptoms below the clinically significant threshold for perinatal depression and anxiety, some of whom may be identified through validated self-report screening questionnaires (Woody et al., 2017). For example, the prevalence of anxiety in pregnancy was 15% when diagnosed by structured clinical interview, but 23% when assessed by self-report questionnaires (Dennis et al., 2017); likewise the prevalence of diagnosed antenatal depression was 13%, but 24% by self-reported questionnaire (Yin et al., 2021). In addition, many pregnant women and new mothers experience more general psychosocial stress that causes them distress (Rallis et al., 2014). For example, a cross-sectional analysis of data from a registry of 1,522 women receiving

antenatal care at a clinic in the USA found that 84% reported psychosocial stress (Woods et al., 2010).

#### 1.1.4 **Policy context**

Although the prevalence of most non-psychotic mental health difficulties is probably similar in the perinatal period to other times of life (National Institute for Health and Care Excellence, 2014), it is considered an important time to identify and treat mental health difficulties, because these can affect not only the woman but also the child and the wider family (NHS England, 2018). In particular, a mother's perinatal mental health difficulties can adversely affect her baby's physical, psychological, mental, emotional and behavioural development (Grote et al., 2010; Laurent et al., 2013; Murray, 1992; O'Connor et al., 2002; Sutter-Dallay et al., 2011). The long-term cost of perinatal depression, anxiety and psychosis has been estimated at £8.1 billion per annual cohort of births in the UK, with 72% of this cost burden relating to the impact on children (Bauer et al., 2014).

Earlier policy in England focused on improving *identification*, notwithstanding the longstanding objections of the National Screening Committee, which continues to recommend that there is insufficient evidence for a national screening programme (Shakespeare, 2001; Solutions for Public Health, 2019). Since 2007 there has been national guidance that universal depression screening questions should be used in routine antenatal and postnatal care (National Collaborating Centre for Mental Health, 2007, 2010; National Institute for Health and Care Excellence, 2014). These are the two 'Whooley' questions: 'During the last month, have you often been bothered by feeling down, depressed or hopeless?' and 'During the last month, have you often been bothered by having little interest or pleasure in doing things?' (Whooley et al., 1997); and the 'Arroll' question: 'Is this something with which you would like help?' (Arroll et al., 2005).

In the past six years there has been a greater policy focus on improving the *response* to perinatal mental health difficulties (Mental Health Taskforce, 2016; National Maternity Review, 2016). There has been targeted government funding to develop specialist community teams, and in-patient services known as Mother and Baby Units (MBUs) (NHS England, 2018). The policy intention is to enable all women to have timely access to appropriate perinatal mental health care when they need it (NHS England et al., 2018), addressing the problem of lengthy waiting times for mothers seeking mental health assessments and psychological therapy (Royal College of Obstericians and Gynaecologists, 2017). This has led to a substantial expansion in access: from a baseline where in 2010 more than 40% of areas in England had no specialist services (NHS England et al., 2018), in 2019 an estimated 80% of areas had specialist perinatal mental health community teams that met national standards (Maternal Mental Health Alliance, 2020). This investment in specialist services

has not yet been matched by investment in increasing access to treatment for more common but less severe perinatal mental health difficulties (Bauer et al., 2022).

# **1.2** Peer support for mental health

### 1.2.1 **Definition of peer support**

Based on a review of over 1,000 studies of peer support in various contexts, charities NESTA and National Voices offered this inclusive definition: "Peer support involves people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance or practical help to each other, often in a way that is mutually beneficial. Peer support is different from other types of support because the source of support is a similar person with relevant experience" (2016, p. 3). Dennis' concept analysis of peer support in healthcare situated it within wider systems: peer support comes from "individuals with experiential knowledge who extend natural (embedded) social networks and complement professional health services" (2003b, p. 322).

Peer support is heterogeneous and not defined by its form. It may take place between individuals or in a group; it may be face-to-face, by telephone, or online; it may be spontaneous or organised; it may involve untrained or trained peers, who may be paid employees or unpaid volunteers; it may be horizontal (between people who support each other) or asymmetrical (where one person is designated as the peer supporter and another as a recipient of peer support); it may exist within a statutory service or in the third sector<sup>1</sup>; and it may be led or facilitated by peers, professionals or other non-peers (Billsborough et al., 2017; Dennis, 2003b; Nesta & National Voices, 2016; Pfeiffer et al., 2011; Solomon, 2004).

# 1.2.2 **Origins of the mental health peer support movement**

Within the field of mental health, peer support is a more complicated construct. Mead et al. defined it as "a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful ... It is about understanding another's situation empathically through the shared experience of emotional and psychological pain" (2001, p. 6). As the modern mental health peer support movement developed in the 1970s, it was closely linked to the wellness-focused 'recovery' movement, the self-identification of people with mental

<sup>&</sup>lt;sup>1</sup> The third sector, also known as the voluntary and community sector, comprises organisations such as charities and community-run groups which are not part of statutory services, although they may receive public funding.

health difficulties as 'survivors' of the mental health system, and the rejection of the 'medical model' of mental illness (Chamberlin, 1990; Mead et al., 2001; Stratford et al., 2019). Drawing inspiration from contemporary civil rights movements, this version of peer support had an explicit human rights-based agenda and sought to combat the marginalisation, oppression and abuse of those affected by mental health difficulties (Chamberlin, 1990; Mead et al., 2001; Stratford et al., 2019). The names of early ex-patient groups (e.g. the Insane Liberation Front) indicate their radical and emancipatory intentions: self-help outside the mental health system developed in parallel with campaigning for an end to discriminatory laws and practices (Chamberlin, 1990).

#### 1.2.3 **Peer support roles within UK mental health services**

Since the late 1980s, peer support roles have been developed *within* mental health services, usually as paid workers (Gillard et al., 2017; Repper & Carter, 2011; Stratford et al., 2019). These roles now exist in most NHS Mental Health Trusts (Gillard et al., 2017). Unlike the ex-patient groups, these peer support relationships are usually 'asymmetrical': a peer support worker draws on shared lived experience to support others who are further from recovery (Davidson et al., 2006; Gillard & Holley, 2014; Repper & Carter, 2011). In the UK these roles may include responsibilities such as skills-building, advocacy, service orientation, group facilitation, and navigating primary care following hospital discharge (Billsborough et al., 2017; Faulkner et al., 2013; Gillard et al., 2014; Gillard & Holley, 2014; Jacobson et al., 2012). Many authors have drawn attention to the challenges of maintaining the distinction between formal peer support roles within services, and other professional roles or tasks that are not predicated on shared lived experience (Davidson et al., 2006; Gillard et al., 2006; Gillard et al., 2014; Mead & MacNeil, 2006; Murphy & Higgins, 2018; Penney, 2018; Repper & Carter, 2011; Solomon, 2004; Stratford et al., 2019).

#### 1.2.4 Third sector mental health peer support in the UK

Peer support is now also widely offered in the UK by third sector organisations that do not necessarily share the activist perspective of the early 'survivor' movement (Billsborough et al., 2017; Faulkner & Kalathil, 2012; Faulkner et al., 2013). Third sector peer support includes groups and oneto-one peer supporters; the latter may be closer to the asymmetrical roles found in mental health services, and they may receive skills training (Billsborough et al., 2017; Faulkner & Kalathil, 2012; Faulkner et al., 2013; Gillard et al., 2014). However, some people in community organisations feel dismayed at the pressure from funders to become more 'professionalised' in their approach, and identify a tension between the formality of professionalism and the relational nature of peer support (Billsborough et al., 2017; Faulkner & Kalathil, 2012; Faulkner et al., 2013; Gillard et al., 2014; Rappaport, 1994).

#### 1.2.5 Frameworks and principles

Mental health peer support takes diverse forms, and the consequent conceptual diversity has been critiqued as posing as risk to its authenticity (Murphy & Higgins, 2018; Stratford et al., 2019). Rather than specifying peer support activities, frameworks have been proposed to map its essential principles. For example, Billsborough et al. (2017) identified six 'core values' for community-based peer support: experience in common; safety; choice and control; two way interactions; human connection; freedom to be oneself. In the context of one-to-one peer support roles within mainstream mental health services, the ENRICH team proposed five principles: relationships based on shared lived experience; reciprocity and mutuality; validating experiential knowledge; leadership, choice and control; discovering strengths and making connections; with an underlying principle of supporting the diversity of lived experience (Gillard et al., 2017).

#### 1.2.5.1 *Reciprocity and mutuality*

The meaning of 'mutuality' or 'reciprocity' within peer support is contested (Murphy & Higgins, 2018). A narrow version, excluding asymmetrical relationships, was articulated by Murphy and Higgins: "full reciprocity, wherein two peers voluntary [*sic*] establish a mutually beneficial relationship to support each other" (2018, p. 444). By contrast, NICE defined perinatal peer support *only* as asymmetrical support, "primarily in one direction with a clearly defined peer supporter and recipient of support" (National Institute for Health and Care Excellence, 2014, p. 215).

A wide version of reciprocity/mutuality combines these two narrow versions (Billsborough et al., 2017; Faulkner & Kalathil, 2012; Faulkner et al., 2013; Gillard et al., 2014; Repper & Carter, 2011). Solomon (2004) and Billsborough et al. (2017) emphasised that 'mutuality' can encompass *mutual benefit* in asymmetrical relationships as well as *mutuality of experience*, because "providing support can in itself be therapeutic and rewarding, contributing to the 'helper's' recovery, redefining the peer worker's own distressing experiences into something that has value" (Billsborough et al., 2017, p. 47). Gillard et al. (2017) focused their definition of 'mutuality' on the *qualities* that peers bring to the relationship: "empathy and mutual respect, a fundamental sense of equal value, and a connection to communities defined by the diversity of culture and experience" (p. 137).

#### 1.2.5.2 Mentoring, befriending and friendship

There have also been debates over the boundaries between peer support and related concepts such as friendship, befriending and mentoring. 'Befriending' has been defined as the matching of a person with mental health difficulties to a volunteer, who may not have peer experience, for regular supportive companionship (Mitchell & Pistrang, 2011). 'Mentoring' implies a helping relationship, for example offering information and guidance, which again does not depend on shared lived

experience (Faulkner et al., 2013). In her classification of social relationships, Dennis (2003b) distinguished between embedded social networks of natural lay helpers (friends, neighbours and coworkers) and created social networks in which peer support can occur: thus peer support and natural lay helpers are mutually exclusive categories. This distinction has been challenged, for example by Bradstreet (2006), who described mutual support from friends with comparable experiences as 'informal' peer support. Other authors have pointed out that in Black, Asian and other minority ethnic communities there may be strong traditions of informal mutual assistance and support within embedded social networks, which may effectively constitute 'peer support' (Edge, 2011; O'Hagan et al., 2009; Seebohm et al., 2010).

Billsborough et al. (2017) defined peer support as including one-to-one peer roles whose aim was befriending or mentoring, relationships in peer support groups which may be experienced as (and indistinguishable from) friendship, and completely unstructured social relationships such as "one-toone interactions that might happen between friends or on a hospital ward" (p. 16). Faulkner and Kalathil (2012) and Faulkner et al. (2013) found that deliberate befriending and mentoring occurred alongside spontaneous friendship in third sector peer support groups. In some groups, the distinction between peer support and friendship was blurred, while in others "a peer is distinguished from a friend by having that 'extra something' that enables them to be able to offer support in an objective way" (Faulkner and Kalathil (2012, p. 23).

In the context of peer supporters working within mental health services, Stratford et al. (2019) saw mentoring as an essential part of their role, which was to "to facilitate, guide, and mentor another person's recovery journey" (p. 4). However, Repper and Carter (2011) and Gillard et al. (2014) pointed out that peer supporters in these formal roles may, in fact, be seen as friends rather than mentors by those receiving support: "especially since they are not only allowed, but also are in fact expected, to disclose personal information and to share intimate stories from their own lives" (Repper & Carter, 2011, p. 398). The variety of terms used to describe these roles reflects a lack of consensus as to their precise nature: for example 'peer support workers', 'peer mentors', 'peer navigators', 'peer educators', or 'peer specialists' (Billsborough et al., 2017; Faulkner et al., 2013; Gillard et al., 2014; Repper & Carter, 2011).

#### 1.2.5.3 Beyond the mental health peer identity

It has also been acknowledged that shared experience of mental health difficulties may be insufficient to establish a 'peer' relationship in some circumstances, and that people who are minoritised by ethnicity, migration status, or sexual orientation may need an "identity specific peer context" (Billsborough et al., 2017, p. v). Some researchers have accordingly defined community

programmes which offer support between people from minoritised communities as 'mental health peer support', even if they were not based on shared mental health experience (Billsborough et al., 2017; Faulkner et al., 2013).

#### 1.2.6 Effectiveness of peer support for mental health

In addition to the lack of consensus about what constitutes peer support, establishing evidence for the effectiveness of peer support for people with mental health difficulties has also been complicated by the heterogeneity of interventions, the variety of outcomes measures used, and the methodological limitations of studies (Chinman et al., 2014; Davidson et al., 1999; King & Simmons, 2018; Lloyd-Evans et al., 2014; Pitt et al., 2013). The most recent systematic reviews have investigated one-to-one peer support in mental health services (19 trials with data from 3,329 participants) (White et al., 2020), and group peer support for people with mental health difficulties (eight trials with data from 2,131 participants) (Lyons et al., 2021). These reviews found modest effects on personal recovery (Lyons et al., 2021; White et al., 2020) and empowerment (White et al., 2020) but not on clinical recovery from mental health symptoms (Lyons et al., 2021; White et al., 2020); both reviews noted that most included studies had a high or unclear risk of bias.

These findings reinforce earlier recommendations that the effectiveness of peer support in mental health services should be evaluated with consistent measures that meaningfully capture what it is actually expected to achieve, such as improvements in subjective distress and psychosocial outcomes including hope and optimism, life satisfaction, wellness, confidence, connectedness, community empowerment and social support (Bellamy et al., 2017; Gillard, 2019; King & Simmons, 2018; Pitt et al., 2013). This fits with the 'CHIME' model of the processes of personal recovery *within* mental health difficulties (Leamy et al., 2011), which placed peer support as the first process within 'connectedness'. Although this model has been criticised for an over-emphasis on positive experiences (Connell et al., 2014), and subsequently refined by Stuart et al. (2017) with the addition of new categories, the importance of connectedness remains unchallenged.

#### 1.2.7 Measuring effectiveness of community-based peer support

Effectiveness research has disproportionately focused on formal peer support roles within mental health services (Penney, 2018). In part this is due to the challenges of identifying appropriate methodology to capture impact in the context of small-scale groups (Billsborough et al., 2017; Faulkner et al., 2013; Kingree & Ruback, 1994). The randomised controlled trial (RCT) is considered the 'gold standard' for effectiveness research (Hariton & Locascio, 2018), but randomisation to receive no support may be considered unethical by community groups who believe their support to be effective, and a contradiction to the principle of mutual help (Billsborough et al., 2017; Faulkner

& Kalathil, 2012; Rappaport, 1994). Billsborough et al. (2017) pointed out that a comparison group design was also unfeasible, because of the difficulties of identifying people who were sufficiently similar to the intervention group (as there are no routine NHS mental health data) and being sure they were not receiving any alternative peer support. The fluidity of the way people engage in community peer support groups also poses real challenges for outcomes evaluation (Billsborough et al., 2017). These challenges are echoed in evaluations of third sector one-to-one support (Moran & Ghate, 2013; Murphy et al., 2008). They were illustrated in a randomised cluster trial which found that home visits by trained volunteers had no impact on the development of postnatal depression: this trial was hampered by inconsistency in the amount and type of support given (Barnes et al., 2006; Barnes et al., 2009; MacPherson et al., 2009). The third sector organisation had refused, on ethical grounds, to allow randomisation at an individual level: "practitioners resist the idea of offering their services in what is then a lottery, particularly if they have a strong belief that their actions lead to positive results" (Barnes et al., 2009, p. 14).

The Side by Side evaluation (Billsborough et al., 2017) used an innovative design to capture impact within 48 community programmes - a time series approach to data collection was combined with a self-controlled case series design for statistical analysis to model the relationship between (1) the amount and type of peer support given or received and (2) outcome measures of hope, self-efficacy, social connection and wellbeing. This evaluation found that giving peer support was more clearly associated with improved outcomes than receiving it. Giving horizontal peer support in a group was associated with a significant improvement in wellbeing, self-efficacy, hope, and increase in contact with friends. This reinforces the findings of a multi-site survey of spontaneous peer support among 628 people with chronic mental health difficulties attending rehabilitation centres in Flanders, which measured perceptions of the amount of peer support given and received (Bracke et al., 2008). That study found that giving horizontal peer support to others was more beneficial to self-esteem and self-efficacy than receiving it, and being a net receiver of support was associated with reduced selfefficacy. The authors of these studies acknowledged the challenge of identifying the direction of effects with their methodologies, as it is possible that people with increased wellbeing would feel more able to offer peer support, or that people with lower self-esteem would be less likely to perceive their social network as supportive.

#### 1.2.8 Take-up of peer support and drop-out

Not everyone with mental health difficulties chooses to use peer support if it is offered, although participation rates are often unreported. A review of peer support for people with serious mental illness found that the majority did not take up an offer to attend a support group, and there were high drop-out rates from groups, leading the authors to conclude that "mutual support appears

currently to be appealing to only a minority, perhaps up to one third, of individuals with severe mental illness" (Davidson et al., 1999, p. 169). Most participants in reported peer support group interventions (primarily in the USA) are White and middle class (Helgeson & Gottlieb, 2000), and this is also true of perinatal mental health peer support groups (Taylor, 2000). This raises the questions of why peer support appeals to some people with mental health difficulties but not to others; who benefits and who does not; which forms of peer support appeal to which people; and why (Davidson et al., 1999).

#### 1.2.9 Benefits and costs for peer supporters

#### 1.2.9.1 *Peer supporters in formal roles*

Studies of the experiences of people working in formal (mostly paid) mental health peer support roles have identified benefits to the peer supporters themselves. The main benefits reported in qualitative studies were: the satisfaction of helping others recover; making meaning out of their own experiences; increased self-esteem and confidence; gaining knowledge and skills which were relevant to their own recovery as well as employment; liberation from the patient role and the stigma of being a mental health service user, replaced with self-acceptance and a sense of belonging to society; and social support from other peer supporters (Moran et al., 2012; Mowbray et al., 1998; Salzer & Shear, 2002; Simpson et al., 2014; Vandewalle et al., 2018). Studies using validated pretest/post-test self-report measures found that participation in a peer support training to prepare for the role significantly increased the peer supporters' perception of hope, self-esteem, empowerment and recovery, as well as employability (Hutchinson et al., 2006; Ratzlaff et al., 2006).

Qualitative work has also investigated peer supporters' perceptions of the personal costs of their role. These included: difficult relationships with the people they were trying to support (who sometimes did not want or value their support); feeling judgemental about the people they were supporting; powerlessness, disappointment and guilt if they felt unable to help the person effectively; lack of clarity about the role and lack of training in how to do it; maintaining boundaries between peer support and friendship; distress from repeated emotional sharing with those they were supporting; and feeling judged or undervalued by other staff (Gillard et al., 2014; Moran et al., 2013; Mowbray et al., 1998; Rebeiro Gruhl et al., 2016; Vandewalle et al., 2018).

#### 1.2.9.2 Volunteer peer supporters

It has long been understood that volunteering has benefits for the volunteers, such as self-esteem; life satisfaction; physical and mental health; coping; and educational and occupational achievement (Casiday et al., 2008; Wilson, 2000). Reviews of one-to-one volunteer support for pregnant women and new parents have likewise reported that the volunteers gained greater self-confidence, self-

esteem and a sense of purpose and satisfaction from helping others; new knowledge and skills that improved employability and affected relationships and parenting; improved mental health; and greater social support (Leger & Letourneau, 2015; McLeish et al., 2016a).

There is little literature that addresses the potential negative consequences of volunteering (Rutherford et al., 2019). Reported costs for volunteers include frustration at not making a difference; feeling unappreciated; and difficulties with the time commitment (Chinman & Wandersman, 1999; Leger & Letourneau, 2015; Trickey et al., 2018). In studies of one-to-one perinatal support, there was an emotional load for some volunteers in being exposed to mothers' distress and social circumstances, making it challenging to maintain boundaries and remain non-judgemental. They could feel guilty about not being able to do more; could feel they had failed if the mother discontinued the support; and the ending of the support relationship caused some volunteers distress if they had feelings of friendship or were concerned about the welfare of the mother (Leger & Letourneau, 2015; McLeish & Redshaw, 2017a; Spiby et al., 2016).

# **1.3** Peer support for perinatal mental health

#### 1.3.1 **Definition of perinatal mental health peer support**

For the purpose of this thesis, perinatal mental health peer support is defined as organised support between two women who both have experience of perinatal mental health difficulties. This peer support may be either:

- asymmetrical: between a trained peer supporter who is more advanced in recovery and a woman who has current perinatal mental health difficulties, or
- horizontal: between two women who both currently have perinatal mental health difficulties, at a peer support group.

The focus of this thesis is on peer support for birth mothers. Fathers and co-mothers also experience mental health difficulties during the perinatal period, and these experiences are important in their own right, but are outside the scope of this thesis.

#### 1.3.2 Characteristics of existing reviews

Peer support is one among a range of interventions that have been tested to help women with perinatal mental health difficulties (O'Connor et al., 2019). In multiple reviews of the quantitative and qualitative evidence, peer support from women with experience of perinatal mental health difficulties has been analysed (a) alongside different interventions such as therapy groups (Dennis, 2014b; Dennis & Dowswell, 2013; Firth et al., 2016; Gillis & Parish, 2019; Goodman & Santangelo, 2011; Morrell et al., 2016; National Institute for Health and Care Excellence, 2014; Scope et al., 2012), and/or (b) using variable definitions of 'peer support', for example support from mothers who do not have experience of perinatal mental health difficulties (Dennis, 2014b; Huang et al., 2020; Jones et al., 2014a; Leger & Letourneau, 2015). The evidence included in these reviews about *peer support from perinatal mental health peers* comes from eleven studies in total: six RCTs carried out in Canada, Taiwan and the USA, and five qualitative studies (or mixed methods studies where the qualitative component was used in the review) carried out in the USA, Canada and the UK, discussed below.

#### 1.3.3 Effectiveness of perinatal mental health peer support

#### 1.3.3.1 Prevention of postnatal depression

Two systematic reviews have included peer support in their examination of the effectiveness of interventions to *prevent* postnatal depression, but in each case only identified one intervention involving support from women with mental health peer experience, a Canadian telephone-based RCT (Dennis et al., 2009). On the basis of this study involving 612 participants, the Cochrane review by Dennis and Dowswell (2013) assessed peer support by telephone as a 'promising' intervention. A National Institute for Health Research systematic review, evidence synthesis and meta-analysis by Morrell et al. (2016) found that evidence for preventative interventions was inconclusive overall, but on the basis of the same study assessed peer support as likely to be one of the most beneficial interventions for women identified as being at high risk of developing postnatal depression.

#### 1.3.3.2 Treatment of postnatal depression and anxiety

A later systematic review of *psychosocial interventions to treat perinatal depression* (Dennis (2014b) used the term 'peer support' to describe two peer support interventions – a Taiwanese RCT of a postnatal peer support group with 60 participants and a Canadian pilot RCT of telephone-based peer support with 42 participants (Chen et al., 2000; Dennis, 2003a) – as well as others offering peer education (Letourneau et al., 2011), mixed peer and non-peer groups (Fleming et al., 1992), and spontaneous peer support within a mental health treatment group (Morgan et al., 1997); the rest of the review addressed completely non-peer interventions. The author concluded that, due to methodological and theoretical weaknesses, evidence for the effectiveness of peer support as a treatment for postnatal depression was equivocal.

A systematic review of *antenatal and postnatal mental health interventions* to underpin NICE's recommendations for practice in England (2014) likewise included the Taiwanese peer support RCT and the Canadian pilot of telephone-based peer support (Chen et al., 2000; Dennis, 2003a), the peer education trial (Letourneau et al., 2011), and the Canadian telephone-based prevention trial (Dennis

et al., 2009) mentioned in section 1.3.3.1 – the authors note that they classify this last study as treatment because all participants who received the peer support to 'prevent' postnatal depression initially scored above a screening threshold which would suggest that many already had postnatal depression. This review found no evidence that peer support had a clinically or statistically significant impact on *anxiety symptoms*, but found low to moderate quality evidence of moderate impact on *depression symptoms* at endpoint. There was no evidence that peer support had a clinically or statistically significant impact on *depression diagnosis* at endpoint; moreover the statistically significant impact on *depression symptoms* had disappeared when participants were followed up 9-16 weeks later.

Another systematic review of the *effect of psychosocial interventions on reducing maternal symptoms of depression* (Firth et al., 2016) included the Canadian telephone-based pilot (Dennis, 2003a) and three group peer support interventions in the USA - two parallel-group RCTs with 44 and 96 participants (Field et al., 2013a, 2013b) and a pilot RCT with 39 participants (Gjerdingen et al., 2013).These were reviewed alongside peer education, telephone support from non-peers, and exercise-based interventions. This review reported that due to the heterogeneity of the interventions, it was underpowered to base strong recommendations for practice.

A systematic review of *group interventions for postnatal depression* (Goodman & Santangelo, 2011) included the Taiwanese peer support RCT (Chen et al., 2000) alongside 10 psychotherapy interventions. While reporting positive effects on depressive symptoms for various group interventions (including interpersonal therapy, cognitive behavioural therapy and peer support), this review also drew attention to heterogeneity of the interventions and the mixed quality of included studies.

A systematic review and meta-analysis of the *effectiveness of peer support on perinatal depression* (Huang et al. (2020) included four RCTs or pilot trials of telephone or group support from mental health peers (Chen et al., 2000; Dennis, 2003a; Dennis et al., 2009; Gjerdingen et al., 2013), alongside six studies of peer education and support given by women who were 'peers' in other ways. This review found that peer support had a small to moderate impact on the symptoms of antenatal and postnatal depression, but did not distinguish between the evidence derived from mental health peers and other peers.

#### 1.3.4 **Evidence from qualitative reviews**

An integrative review (Gillis & Parish, 2019) of *group interventions for postnatal depression* included two small qualitative studies of mental health peer support in the USA (Anderson, 2013) and Canada (Montgomery et al., 2012) alongside other interventions; the specific contribution of peer support

cannot be identified in their conceptual model. Likewise, a meta-ethnography of *peer support in the context of perinatal mental illness* (Jones et al., 2014a) included the same study of a Canadian perinatal mental health peer support group (Montgomery et al., 2012), and otherwise drew on four studies where support was not given by mental health peers (Mauthner, 1995; Tammentie et al., 2004) or where women were describing their support preferences but not necessarily experiences (Letourneau et al., 2007; Raymond, 2009).

By contrast, a qualitative synthesis of *group interventions for postnatal depression* (Scope et al., 2012) synthesised the findings of three studies of professionally-facilitated peer support groups, in the USA (Duskin, 2005) and UK (Eastwood, 1995; Pitts, 1999), and one paper that incidentally mentioned peer support (Beck, 1993). This analysis was kept distinct from concurrent analysis of two papers on cognitive behavioural therapy groups within the overall review. In this synthesis, the peer support results were organised into shallow themes: 'community' (overcoming isolation, gaining hope of recovery, and gaining confidence by leaving the house), 'social comparison and proto-typing' (realising that others have similar experiences), and 'practicalities and knowledge' (learning to recognise the symptoms of postnatal depression). Some adverse effects of peer support were reported: mothers feeling over-reliant on the group, and having anxiety reinforced by social comparison with another participant who was not getting better.

#### 1.3.5 Limitations of evidence

These reviews contextualise perinatal mental health peer support within the broader landscape of potential interventions. By reviewing peer support alongside other interventions they draw attention to some commonalities that may underlie contact with peers in various scenarios including therapy groups, but also underline the limited evidence base for the effectiveness of perinatal mental health peer support. Most of these reviews are further limited by their focus on postnatal depression, to the exclusion of other perinatal mental health difficulties. As Goodman and Santangelo (2011) pointed out, systematic reviews focused on effectiveness leave unanswered the questions of *for whom* the intervention is most effective, and *how* and *why*.

Qualitative meta-syntheses have potential to shed light on some of these questions by exploring the experiences of participants. However, only one of the qualitative reviews (Scope et al., 2012) separated peer support from other interventions. The two UK studies in that review were over 20 years old and methodologically weak - one (Eastwood, 1995) was based on the researcher's observations without direct evidence from the 13 women who had attended group sessions, and the other (Pitts, 1999) was based on open text answers to evaluation questionnaires from 34 women, samples of which were presented as a list without further analysis.

Apart from Scope et al. (2012), there was little attention given by these reviews to the potential negative aspects of peer support, reflecting the lack of attention to negative impacts in included studies. Morrell et al. (2016) reported on the potential negative aspects of group and one-to-one support in general, but not peer support specifically. In a report on parents supporting other parents, based on a rapid evidence review and stakeholder interviews, NESTA identified six priority research questions for the sector, including "What are the potentially harmful consequences of peer dynamics and how can we mitigate them?" (Bibby & Deacon, 2020). Likewise Dennis (2014a) called for peer support programmes to identify mechanisms through which negative effects may occur so that they can be prevented through revisions to volunteer training.

#### 1.3.6 NHS and third sector perinatal peer support in England: policy and practice

Perinatal mental health peer support is underdeveloped in England, although it has been given impetus by the policy developments described in section 1.1.4. The national maternity and mental health strategies (Mental Health Taskforce, 2016; National Maternity Review, 2016) and NICE guidelines (National Institute for Health and Care Excellence, 2014) do not include recommendations for perinatal mental health peer support. However, in 2017 the Royal College of Obstetricians and Gynaecologists recommended that commissioners should consider working with the third sector to introduce trained peer supporters (Royal College of Obstetricians and Gynaecologists, 2017). In 2018, guidance for health visitors suggested that they could improve maternal mental health by developing peer support and working with parent volunteers (Public Health England, 2018). In 2021, the Royal College of Psychiatrists issued guidance that included peer support workers in the minimum staffing recommendations for community and in-patient perinatal mental health services, and also recognised the importance of third sector peer support as part of the care pathway:

"The third and voluntary sector plays an important role in providing accessible, often peer-led, support to women experiencing perinatal mental health problems across all ranges of severity ... For women with mild problems that do not require access to perinatal mental health services, these organisations may provide the primary source of support. For women accessing perinatal mental health services in primary or secondary settings, voluntary sector organisations can add value in terms of peer-led interventions ... In addition, they can provide a safety net and on-going support for women stepping down from perinatal mental health services." (2021, p. 30)

Current perinatal mental health peer support in England includes some formal roles in Mother and Baby Units and community teams (Wood, 2020), and peer support offered outside the NHS by an increasing number of third sector organisations (Royal College of Psychiatrists, 2021). Most of these third sector programmes are small scale and many operate without an evaluated delivery model

(McPin Foundation, 2018; Moran, 2020). Peer support may be their unique focus, for example The SMILE Group (2017), or it may be part of a range of services offered, for example Acacia Family Services (2020); Bluebell (undated-b); Mothers for Mothers (2020).

In 2019, MIND and McPin published quality assurance principles for third sector organisations, based on a consensus methodology and framed for reflective practice rather than measurable standards (MIND & McPin Foundation, 2019). These principles declared that good perinatal peer support is safe and nurturing; is accessible and inclusive; complements rather than replicates the work of clinical mental health services; provides opportunities for meaningful involvement of people with lived experience and peer leadership; and benefits everyone involved, including peer supporters. MIND published similar principles for peer support in NHS perinatal mental health services (Wood, 2020). In 2020, the Hearts and Minds Partnership was created by three third sector organisations as a network to map local groups, share learning, and develop training (Hearts and Minds Partnership, 2020).

#### 1.3.7 The Parents in Mind peer support programme

In 2016, national parent support charity NCT received funding from the Department of Health to pilot a blended model of one-to-one and group perinatal mental health peer support from trained volunteers. This programme, called 'Parents in Mind', was established at three sites and was the setting for the primary research reported in this thesis.

### 1.4 Research rationale, aims, objectives and structure

#### 1.4.1 Rationale

The consensus principles and networking described in section 1.3.6 suggest a perinatal mental health peer support sector in the UK that is beginning to develop a cohesive identity. The review evidence summarised in sections 1.3.3 and 1.3.4 indicates the limitations of the current evidence-base for perinatal mental health peer support as distinct from non-peer social support or psychological therapies. There are, as yet, no robust evaluations of third sector programmes in the UK that would provide the evidence needed for replication or future development. In particular there is a dearth of research about the reasons why some women choose to use perinatal mental health peer support or not to use it, and the potential for peer support to have both positive and negative impacts on both the women who use it and the peer supporters who give it.

The rationale for this thesis was the need to develop this limited evidence base, in order to assist the future development of safe and effective perinatal mental health peer support in the third sector.

# 1.4.2 **Aim**

The overall aim of this research was to deepen understanding of what it is about perinatal mental health peer support offered or led by trained volunteers that works, for whom, in what circumstances, in what respects, and why.

# 1.4.3 **Objectives**

Table 1 shows the research objectives and how they were met through the two components of the thesis: (a) a **realist review** of community-based perinatal mental health peer support (Chapters 3-5) and (b) a **primary research study**, which was a theory-based evaluation of Parents in Mind (Chapters 6-10).

#### Table 1 Research objectives and how these were met

Research objective	How this was met	Chapters
To review the literature on the take-up and use of perinatal mental health peer support	Realist review	3-5
To explore the process of implementing a pilot perinatal mental health peer support programme (Parents in Mind).	Primary research	6-7
To explore the mechanisms underlying the take-up of	Realist review	3-5
peer support by mothers with perinatal mental health difficulties, and the contexts in which these operate.	Primary research	6, 8
To explore the positive and negative mechanisms	Realist review	3-5
underlying the impact of perinatal mental health peer support <i>on mothers receiving it</i> , and the contexts in	Primary research	6, 9
which these mechanisms operate to produce outcomes.		
To explore the positive and negative mechanisms underlying the impact of perinatal mental health peer support <i>on trained volunteer peer supporters giving it</i> , and the contexts in which these mechanisms operate to produce outcomes.	Primary research	6, 10
To explore whether and how the mechanisms affecting	Realist review	3-5
the take-up and impact of peer support differ in two models of peer support: a peer-led group or one-to-one.	Primary research	6-10
To develop a theory of change for third sector perinatal	Realist review	3-5
mental health volunteer peer support.	Primary research	6-10
	Discussion	11

### 1.4.4 **Relationships between the realist review and the primary research**

There was iteration between theory-identification and theory-testing within and between the realist review and the primary research. In the realist review, potential programme theories for perinatal mental health peer support were first hypothesised (initial theoretical model) and then tested against the literature on empirical studies of perinatal mental health peer support (final theoretical model). In the primary research, potential programme theories for Parents in Mind were first hypothesised (initial theory of change) and then tested against analysis of the data collected (final theory of change).

Although they are presented sequentially in this thesis, the realist review and primary research were carried out in parallel. The different stages, and how they interacted, are shown in Figure 1. The terms used in Figure 1 and section 1.5 are explained in Chapter 2.





#### 1.4.5 **Thesis outline**

Chapter 2 describes the critical realist approach and the methodology. Chapter 3 introduces the methods of the realist review. Chapter 4 presents part one of the realist review results: the narrative results of exploratory searching, from which candidate contextual factors, mechanisms and outcomes were hypothesised. Chapter 5 presents part two of the realist review results: the empirical studies of perinatal mental health peer support and the final theoretical model. Chapter 6 describes the methods of the primary research. Chapters 7-10 present the results of the primary research. Chapter 7 describes the research participants and the implementation of the pilot, and presents the theory of change. Chapter 8 describes the findings related to the take-up of peer support in different contexts. Chapter 9 describes the findings on the positive and negative mechanisms of change within Parents in Mind for mothers receiving peer support, the contextual factors that triggered those mechanisms and the outcomes they produced. Chapter 10 describes the findings on positive and negative mechanisms of change within Parents in Mind for the volunteers, the contextual factors that triggered those mechanisms and the outcomes they produced; it also presents findings about volunteers' experiences of support to manage challenges. Chapter 11 discusses the findings in the light of the wider literature. It considers the complexity of peer support as an intervention, the strengths and limitations of the research, and the implications for programmes and further research.

#### **1.5 Reflexivity**

This study relied on researcher-as-instrument, so it was important to reflect on how my own values, characteristics, and experiences could affect the research process, while accepting (using realist logic) that such self-awareness will also be partial. For a critical realist, the goal of this reflection is firstly, to recognise these influences in order to see past them, and secondly, to harness them as a potential source of insight: "Rather than treating subjectivity as a variable to be controlled and ideally reduced to zero, realists see it as a component of the actual process of understanding " (Maxwell, 2012, p. 98). This process was supported by writing reflective memos.

Professionally, I have 27 years' experience of working for third sector organisations concerned with pregnancy and parenthood, focusing on parents and babies affected by inequalities in opportunities and outcomes. As an academic researcher I have previously carried out large qualitative studies of perinatal volunteer and peer support, involving 14 third sector programmes working with diverse mothers experiencing a range of vulnerabilities. I was also part of an advisory group for an evaluation of Birth and Beyond Community Supporters, an earlier volunteer and peer support pilot programme (not for mental health difficulties) run by NCT. These professional experiences have

given me insight into the complexity of the challenges faced by many pregnant women and new parents; belief in the value of mothers supporting each other in the perinatal period; awareness of the capacity of the third sector to offer essential forms of support in the transition to parenthood; understanding of some of the challenges of sustaining work in community organisations whose funding is largely dependent on short-term grants and contracts; and admiration for the skills and dedication of those who lead these organisations.

Personally, my outlook on this topic is shaped by my identities as a woman, born in the UK, White, middle class, educated and feminist. Most saliently for this research it is shaped by the fact that I am a mother of three children, but have no personal experience of perinatal mental health difficulties. On the contrary, pregnancy and early motherhood were joyful times for me. I do, however, have experience of living with a partner who had poor mental health in the perinatal period. I also have experience as a volunteer supporter for a new mother with severe postnatal depression, through a host family scheme organised by the charity Freedom from Torture. This has given me some personal insight into the emotional challenges of supporting people with perinatal mental health difficulties.

In the context of the increasing emphasis on 'peer research' in mental health (for example, through the work of the McPin Foundation (https://mcpin.org/)), my lack of personal lived experience of perinatal mental health difficulties could be seen as limiting my ability both to build rapport in interviews with mothers and volunteers in order to generate trustworthy data, and to analyse data insightfully (Beresford, 2007; Harding et al., 2012). This understanding of the benefits of peer research draws on feminist approaches to methodology that seek to collapse the distinction and therefore power imbalance between interviewer and interviewee (Oakley, 1981). Oakley herself later (Oakley, 2000, p. 15) quoted Pawson's critique of this logic taken to an extreme: "We are well down the path to solipsism here, and in a world in which only men can interview men, scientists understand scientists, fascists involve with fascists, and Oakley makes sense only to Oakley" (Pawson, 1989, p. 320). Within peer research (as within peer support) there is also the challenge of defining who counts as a peer, given the multiple identities held by both a peer researcher and their interviewee (Terry & Cardwell, 2016). This is intrinsically an issue of real complexity in perinatal mental health, because of the very wide variety of affective and psychotic mental health difficulties and levels of distress that mothers experience in the perinatal period, in addition to all the other aspects of their identities.

Maxwell (2012, p. 102) cautions interviewers to "avoid assuming that solidarity is necessarily a matter of similarity". It might be assumed that interviewees who feel stigmatised might be less
willing to talk openly to a person who is not affected by the same stigma. My own experience of interviewing Black African mothers living with HIV (McLeish & Redshaw, 2016) indicated that where a non-peer researcher is introduced to mothers by a peer support organisation, that can be a sufficient basis of trust for mothers to speak freely about the stigmatised condition. Moreover it is sometimes useful in interviews to be able adopt a position of naiveté rather than insider-knowledge, in order to draw out aspects of interviewee's experience and full explanations in their own words, rather than relying on the assumption of shared knowledge (Kvale, 1996).

The data analysis for this research was not restricted to representing the experiences of mothers with perinatal mental health difficulties, but involved going deeper than the 'empirical' level of reality to search for mechanisms operating at the 'real' level. This reduced the relevance of personal experience, which can limit the lens of analysis as much as expanding if used uncritically (Terry & Cardwell, 2016). It may that the greatest benefits of peer research are not directly related to the quality of the research, but are emancipatory and ethical – peer-researchers themselves may gain confidence, skills and status, and participatory research can reduce the objectification of marginalised populations through collaborative knowledge-creation (Terry & Cardwell, 2016).

For these reasons, a non-peer researcher is not necessarily at a methodological disadvantage, but it was important that findings resonated with mothers who had lived experience of perinatal mental health difficulties. To avoid participant burden, this was not done with the supported mothers or volunteers interviewed. Parents in Mind staff and members of the project advisory group included women with lived experience. The structure of the evaluation created opportunities to present developing findings to them, and their questions, interpretations and perspectives during the pilot informed subsequent data analysis.

This doctorate was jointly funded by NCT (through their programme grant from the Department of Health) and City, University of London. In their capacity as funder, NCT required an evaluation report at the end of the Parents in Mind pilot in 2019, which was written jointly with the NCT's Research and Evaluation Manager (McLeish & Hann, 2020). This short report summarised the programme, changes in mothers' mental health during their use of peer support, the positive and negative impacts of peer support described by mothers and volunteers, and key learning from the three pilot sites; it included simple logic models and case studies. It was written after the background searching for the realist review and the focused coding of the Parents in Mind primary data, and was not explicitly realist. Once the evaluation report was submitted, NCT/Parents in Mind staff had no further contact with the doctoral research, which proceeded with the search for empirical studies in the realist review, theoretical analysis of the primary data using context-mechanism-outcome

configurations, and the construction of a full theory of change for Parents in Mind using critical realist principles.

Finally, it is important to be transparent about my motivation for undertaking this research. Evaluating Parents in Mind was an opportunity to build on my previous research, which had convinced me of the subjective value of mothers supporting each other. My aim was to generate findings that could be of practical use to third sector organisations as they develop their peer support. Undertaking this evaluation in the context of a PhD was also an important motivating factor. Although I have carried out and analysed hundreds of qualitative interviews in third sector and academic research studies, I am self-taught and have a different professional background (law) that does not provide relevant methodological training. Doctoral research presented the opportunity of deepening my theoretical and methodological understandings, and also improving my practice.

## **1.6 Chapter summary**

Perinatal mental health difficulties are common and can have a serious impact on the mother and her family. Peer support from others with similar experiences is used in other mental health contexts, and has been shown to have benefits for subjective recovery although not for measurable change in the symptoms of diagnosed mental health difficulties. Peer support has been proposed as an intervention that could benefit women with perinatal mental health difficulties, and there is some evidence for effectiveness, alongside a small amount of evidence of potential negative impacts for some women. There is also some evidence of both benefits and unintended consequences for peer supporters. This thesis aims to develop the limited evidence base for third sector perinatal mental health peer support through a realist review and a theory-based evaluation of the Parents in Mind pilot.

# 2 Methodology

## **Chapter overview**

This chapter gives a brief overview of critical realism as the theoretical paradigm for this research. It explains the use of theory-based evaluation as the framework for the primary research. It introduces the realist review, and the design of the primary research. It explains the use of mixed methods, and techniques drawn from realist principles or borrowed from Grounded Theory. Finally it considers the quality criteria that are applicable.

## 2.1 Theoretical orientation – critical realism

## 2.1.1 The critical realist paradigm

The research reported in this thesis works within a critical realist paradigm, derived from the philosophy of Bhaskar (1975, 2008). Critical realism posits ontologically the independent existence of a pre-social reality, combined with a relativist epistemology, so that science is "the systematic attempt to express in thought the structures and ways of acting of things that exist and act independently of thought" (Bhaskar, 2008, p. 242). Unlike positivism, critical realism does not conflate existence with empirical observation nor use observable event regularities to infer causation; and unlike constructivism, it does not restrict reality to human constructs, nor reject explanation in favour of hermeneutics and description (Archer et al., 2016; Sayer, 2000). Epistemic relativism implies that because knowledge is situated in a social, cultural and historical context (Archer et al., 2016), it must be understood as being "partial, incomplete, and fallible" (Maxwell, 2012, p. 5). Within these necessary limitations, the task of social scientists is "construing rather than 'constructing' the social world" (Sayer, 2000, p. 11).

#### 2.1.2 **Ontological depth and generative causation**

Critical realists distinguish three ontological domains. In Bhaskar's typology, the *empirical domain* represents reality as consisting of things and events that we experience or observe; the *actual domain* represents reality as consisting of things and events whether or not experienced or observed; and the *real domain* includes both things and events (whether or not experienced or observed) *and* the underlying mechanisms that cause them (Bhaskar, 2008; Porter, 2015). The primary task of the critical realist is to investigate underlying causal mechanisms in the real domain (Bhaskar, 2008; Clark et al., 2008; Sayer, 2000).

The social world is understood as an open system characterised by 'emergence' where latent mechanisms (M) are activated by particular contexts (C) and interact with one another in complex

ways to generate new phenomena, including outcomes (O) (Bhaskar, 2008; Clark et al., 2008; Sayer, 2000). There may be patterns in the action of mechanisms, known as 'demi-regularities', but these are not laws with predictive value because, unlike the closed system of a natural science experiment, individual mechanisms cannot be isolated from the interference of other mechanisms, and there will always be contexts in which an individual mechanism will *not* be activated (Danermark et al., 2002; Westhorp, 2018). The natural and social worlds are understood as 'stratified', with all human thought, agency and action being embedded within social, biological and physical processes (Bhaskar, 2008; Pawson & Tilley, 1997). Causal mechanisms may operate within and across different strata: for example, social phenomena may be the emergent products of human interaction and biological phenomena (Archer, 1995; Sayer, 2000). Social structures will in turn affect the psychological mechanisms involved when individuals make choices (Porter, 2015).

### 2.1.3 **Reasons for choosing a critical realist approach**

Critical realism's characterisation of knowledge claims as provisional offers a valuable perspective from which to consider mental health, because of the potential plurality of causation in mental health difficulties (and recovery) inherent in the current bio-psycho-social model (Bergin et al., 2008; Pilgrim & Bentall, 1999; Sword, 2012). Its conception of the stratified nature of reality focuses attention on how the outcomes of a social intervention aiming to improve mental health may be affected by interactions between individual factors (such as beliefs, motivation and meaning) and structural/systemic factors (such as cultural norms) (Clark et al., 2008; McEvoy & Richards, 2003; Sword, 2012). There are a range of potential mechanisms that could be active within peer support (Dennis, 2003b; Gillard et al., 2015) and a range of theoretical explanations for these (Davidson et al., 1999; Salzer & Shear, 2002) (see Chapter 4). A critical realist approach enables detailed investigation of these mechanisms in perinatal mental health peer support and how they may be affected by contextual issues to produce different positive or negative outcomes for different individuals.

#### 2.1.4 **Definitions of context, mechanism and outcome**

The definitions of context and mechanism continue to evolve (Lacouture et al., 2015). In this thesis, 'context' is defined as factors at macro-, meso- or micro-level that cause mechanisms to be activated (or not to activate), such as socio-cultural values and norms (macro), the setting for the programme (meso), and the personal characteristics of those involved (micro) (Lacouture et al., 2015; Pawson, 2006b). 'Mechanism' is defined as the reasoning and reactions (cognitive and affective responses) of mothers and volunteers in response to the resources provided by the programme (Pawson et al., 2011; Westhorp, 2018). 'Outcome' is defined as the intentional or unintentional consequence of this

reasoning or reaction. When considering take-up of peer support, 'outcome' is defined as a mother participating in the peer support at least once.

### 2.2 Framework - theory-based evaluation

The primary research was guided by the Medical Research Council (MRC)'s model of process evaluation for complex interventions (Moore et al., 2014, 2015), and used the framework of theorybased evaluation (Coryn et al., 2011). Parents in Mind fell within the MRC's definition of a 'complex intervention' because of its multiple interacting individual and social components and the flexibility of the model (Moore et al., 2015).

#### 2.2.1 **Programme process evaluation**

Programme evaluation has been defined as "the systematic collection of information about the activities, characteristics and outcomes of programs to make judgements about the program, improve program effectiveness, and/or inform decisions about future programming" (Patton, 2002, p. 10). It has the essentially idealistic purpose of gathering evidence to increase our ability to improve the quality of people's lives (Chen, 2005). One of the earliest classifications of evaluation activities was the division into formative and summative evaluation (Scriven, 1967). Summative evaluation judges the merits of a programme, typically at its end, while formative evaluation considers how the implementation of the programme can be improved, typically during the programme, by "providing information for mid-course correction" (Kubisch et al., 1995, p. 16).

Process evaluation, which is a type of formative evaluation (Weiss, 1995), has traditionally been focused on assessing what was implemented. Frameworks have been developed to guide implementation-focused process evaluations, for example by Baranowski and Stables (2000), Linnan and Steckler (2002), and Saunders et al. (2005). Moore et al. (2015) noted that while there are no criteria by which to judge the merits of these competing frameworks, there are common concepts such as fidelity (the extent to which the intervention was delivered as planned), reach (whether and how the target population came into contact with the intervention) and dose (the extent to which participants were offered and actively engaged with the intervention).

The MRC guidance went further, defining process evaluation as "a study which aims to understand the functioning of an intervention, by examining implementation, mechanisms of impact, and contextual factors" (Moore et al., 2014, p. 8). As well as the traditional implementation questions, it urged that exploring the mechanisms of change "is crucial to understanding both how the effects of the specific intervention occurred and how these effects might be replicated in future interventions"

(Moore et al., 2015, p. 2). The primary research reported in this thesis is a process evaluation within this wider definition. The MRC's model of process evaluation is shown in Figure 2.



**Figure 2 Key functions of process evaluation and relations among them** *Reproduced from Moore et al., (2015) in accordance with the terms of a Creative Commons attribution (CC BY 4.0) licence.* 

The Parents in Mind pilot was an open system, for which a summative evaluation was not appropriate because there was no stable intervention model. The three sites were established in a phased sequence with the intention of transferring learning between them, and there were significant changes made during the pilot (see section 7.5). This evaluation also contributed to the openness of the intervention. Key learning points were shared with programme staff throughout the pilot, in the spirit of developmental evaluation (Patton, 2010) and learning evaluation (Balasubramanian et al., 2015), which emphasise the evaluator's role in providing rapid feedback to guide iterative organisational development. This is recognised by the MRC as an appropriate evaluative role in the process evaluation of a pilot (Moore et al., 2015).

## 2.2.2 Principles of theory-based evaluation

Theory-based evaluation is one of the approaches recommended by the MRC for investigating a programme's mechanisms of change (Moore et al., 2014). Theory-based evaluation has developed from the work of Chen and Rossi (1980), Chen (2005, 2006, 2012), and Weiss (1995, 1997) and goes by many names, including theory-of-change evaluation and program-theory evaluation (Coryn et al., 2011). Although different versions of theory-based evaluation are operationalised in slightly different ways, they share a common purpose: "not only knowing whether a program is effective or efficacious (i.e. causal description; *that* a causal relationship exists between A and B), but also explaining the program's underlying causal mechanisms (i.e. causal explanation; *how* A causes B)" Coryn et al. (2011, p. 203).

To achieve this explanation, theory-based evaluation uses an initial 'theory of change' to design and conduct the evaluation. This is used to formulate evaluation questions and is tested against data gathered from the programme to create a final theory of change (Coryn et al., 2011). 'Theory' in this context refers how the programme is believed or intended to work: a conceptualisation of the underlying causal mechanisms that can bring about the evaluated outcomes and "upon which [the programme] can develop a treatment or intervention to meet a need" (Chen, 2012, p. 18).

### 2.2.3 Theory-based evaluation and critical realism

Although theory-based evaluation practice has developed independently of theoretical considerations (Coryn et al., 2011), realism is a natural philosophical foundation for its quest to understand mechanisms of change (McEvoy & Richards, 2003). Applied to programme evaluation, the logic of realism is that if an intervention is found to succeed, "it is not the intervention but the mechanism that needs to be transferred" (Marchal et al., 2012, p. 206).

Underpinning a theory-based evaluation with an explicitly realist approach enables the evaluator to avoid the common trap of conflating programme actions with mechanisms (Pawson & Tilley, 2004; Weiss, 1997), which are often represented in a programme's logic model as "unexplained 'causal arrows'" (Astbury & Leeuw, 2010, p. 367). Social programmes offer resources to participants, but it is participants' reasoning and reactions to these resources, not the resources themselves, which constitute the programme mechanisms (Pawson et al., 2011). The realist approach also emphasises the importance of understanding mechanisms as emergent phenomena affected by context, as well as by interaction with other mechanisms which may enhance or cancel out each other's effects, thus causing programmes to work in different ways in different circumstances (Bhaskar, 2008; Clark et al., 2008; Pawson & Tilley, 1997; Wong et al., 2016). A critical realist theory-based evaluation therefore seeks to expose and understand a programme's inner workings, to optimise the nuanced understanding that will enable successful replication (Astbury & Leeuw, 2010; Moore et al., 2015).

### 2.2.4 **The problem with black box evaluation**

This attention to underlying causal processes addresses the weakness of 'black box' evaluation, which aims to establish whether a programme 'works' by assessing inputs and measuring outcomes, without generating insight into how it works, for whom or why. By contrast, theory-based evaluation is sometimes described as 'clear box' evaluation, because it focuses on precisely these questions of inner logic (Astbury & Leeuw, 2010).

Black box evaluation arranges research methods hierarchically, with quantitative methods considered superior to qualitative, and RCTs at the top of the pyramid (Spencer et al., 2003). This approach was characteristic of mid-twentieth century programme evaluation (Pawson & Tilley,

1997), and remains at the heart of the contemporary evidence-based practice movement (Porter & O'Halloran, 2012). The commitment of black box evaluation to experimental design has been critiqued by realists Pawson and Tilley as "a heroic failure" (1997, p. 8). In particular the evidential power of an RCT (devised to be implemented in a closed system) is limited in the context of programme evaluation, because programmes are open systems, "in which many factors additional to the intervention itself, including those relating to organizational structure, cultural mores, resource capacity, and the interpretations and actions of the individuals involved, will affect the effectiveness of the intervention" (Porter & O'Halloran, 2012, p. 19). Consistency and control, as required by programme evaluation based on sound experimental design, are directly at odds with creative adaptation to changing circumstances, which is fundamental to good practice in programme delivery (Greene et al., 2001; Pawson et al., 2011). Randomised designs therefore tend to produce different results in different real-world contexts, giving rise to the appearance that no programme 'works' when replicated (Pawson & Tilley, 1997).

While the MRC emphasises the quest for mechanisms as a key part of process evaluation, it envisages process evaluation as taking place alongside an RCT, following an initial stage of piloting (Moore et al., 2015). There has been lively debate as to whether a 'realist RCT' of a complex healthcare intervention is possible and desirable (Bonell et al., 2012; Bonell et al., 2016; Jamal et al., 2015; Porter et al., 2017; Porter & O'Halloran, 2012) or oxymoronic and ontologically incoherent (Marchal et al., 2013; Van Belle et al., 2016). Bhaskar saw critical realism as liberating social sciences from the "dead hand" of ideologies derived from experimental sciences and "theories secreted by the flat undifferentiated ontology of empirical realism" (Bhaskar, 2008, p. 253). Even proponents of the realist RCT accept that it can only be used to test the efficacy of an intervention (in tightly controlled conditions) rather than effectiveness (in open, real world conditions) (Porter et al., 2017).

#### 2.2.5 Why not realist evaluation?

Realist evaluation is another approach recommended by the MRC (Moore et al., 2014). It is a refinement of theory-based evaluation and shares many common features, including using a common language of context, mechanism and outcome (Pawson, 2013; Wong et al., 2016). Its originators Pawson and Tilley (1997) coined the description of the evaluator's task as understanding what works, for whom, in what circumstances, in what respects, and why.

Subsequent development of realist evaluation has sought to distinguish it both from theory-based evaluation and from critical realism (particularly Bhaskar's later philosophy) (Blamey & Mackenzie, 2007; Pawson, 2013). It has, however, has been convincingly argued that these distinctions have been overstated (Porter, 2015). In practice, evaluation researchers often use the terms 'theorybased evaluation' and 'realist evaluation', and the vocabulary and techniques associated with them,

interchangeably (Marchal et al., 2012). Pawson has recently advised researchers debating the distinction between 'scientific' and 'critical' realism that they should "just get on with some decent empirical work and call it 'realist informed'" (Pawson, 2021).

There were two main factors that influenced the decision to situate this research as a critical realist theory-based evaluation instead of a realist evaluation. Firstly, Blamey and Mackenzie (2007) noted that realist evaluation is generally used to investigate the mechanisms within the 'change model' - "what causal processes are expected to happen to attain program goals" (Chen, 2012, p. 18), but not the 'action model' – "what actions must be taken in a program in order to produce desirable changes" (Chen, 2012, p. 18). Theory-based evaluation explicitly seeks to capture both change model and action model, consistent with the goals of this research.

Secondly, Pawson and Tilley took a stance on realist data collection which is not entirely appropriate for this research. They asserted that when interviewing a participant, "the researcher's theory is the subject matter of the interview, and the subject (stakeholder) is there to confirm, to falsify, and above all, to refine that theory" (Pawson & Tilley, 1997, p. 155). If this were to be applied as the guiding principle to interviews with those giving and receiving mental health peer support, it would fail to honour their lived experience and would undervalue the subjective meanings these experiences have for them. Porter (2015) argued that for an evaluation informed by critical realism, in contrast to a strict 'realist evaluation', there is an ethical dimension related to how the programme enhances or inhibits the realisation of human potential; consequently the "the phenomenological experiences of those who are its putative beneficiaries; those whose behaviour it is intended to alter; and/or those who are expected to implement it should be at the core of the evaluative exercise" (2015, p. 79). Therefore this research drew strongly on the methodological insights of realist evaluation without tying itself exclusively to the full methodology.

#### 2.2.6 The importance of 'dark logic'

Social programmes have the capacity to cause unintended harms (Merton, 1936), which may be masked by untested assumptions of benefit (Oakley, 2000). In a theory-based evaluation, the theory of change should identify potential negative consequences of the intervention (Coryn et al., 2011; Weiss, 1997). Applying a realist approach, Bonell et al. (2015) called for evaluators to develop a 'dark logic' model theorising the potential contexts and mechanisms that may lead to negative outcomes, and to investigate these during the evaluation, as well as remaining open to the identification of unanticipated harms. They argued that this can improve interventions by enabling those delivering them to take steps to reduce the risks. Although the term 'logic model' has traditionally been applied to a *descriptive* sequence of inputs, activities, outputs and outcomes (i.e. no causal

mechanisms), in contrast to an *explanatory* 'theory of change' (Astbury & Leeuw, 2010), Bonell et al.'s evocative term 'dark logic' has been adopted in this thesis for those parts of the theory of change related to potential negative consequences.

#### 2.3 Choosing a realist literature review

Realist review, also known as realist synthesis, is a methodology for reviewing literature that aims to *explain* social programmes by focusing on how they work, for whom, in what circumstances, in what respects, and why. Realist review applies the same principles as realist evaluation, mapping generative causation in order to build an "ontologically deep understanding" of programmes (Jagosh, 2019, p. 361). The approach was initially developed by Pawson (Pawson, 2006b; Pawson et al., 2005) and consensus publication standards for realist review have been published by Wong et al. (2013) on behalf of the Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES I) project.

Building on the realist logic that programmes are "theories incarnate" (Pawson, 2006b, p. 23), realist review seeks first to hypothesise the programme theories (C-M-O configurations) that may be at work. Realist reviewers use 'middle range theory' (Merton, 1967) (i.e. explanatory theories which are capable of being a ground for prediction and tested with data) to identify potential programme mechanisms and outcomes (Jagosh et al., 2014). Having created an initial theoretical model, the realist reviewer then tests it against empirical data gathered in the review to create a final theoretical model of how and why the programmes work. This enables conclusions to be drawn about how the programmes may be offered most effectively in order to inform future versions of the intervention (Pawson, 2006b).

Realist review was chosen for its philosophical and practical coherence with theory-based evaluation, and to fill the evidential gap identified in Chapter 1. A theory-based evaluation tests the programme's theory of change, so the first step is identification of potential programme theories (Coryn et al., 2011); one source of these was existing research on comparable programmes and social science theory (Patton, 2010), as synthesised in the realist review. Using a realist approach to synthesising the literature on community-based perinatal mental health peer support enabled a detailed exploration of what has been reported about who participates in these forms of support and why, who benefits, the positive and negative ways in which participants may be affected, the causal pathways for any changes, and the circumstances in which change happens. Integrating contexts was particularly important as these have not previously been included in peer support change models, for example those developed for peer workers in mental health services (Gillard et

al., 2015) or for recovery narratives that might be shared in peer support (Rennick-Egglestone et al., 2019a).

# 2.4 Primary research study design: mixed methods theory-based evaluation

## 2.4.1 Mixed methods

The primary research used both qualitative and quantitative methods, which is standard practice for a theory-based process evaluation (Chen, 2006; Greene et al., 2001) and is recommended by the MRC for evaluation of a pilot: "basic quantitative measures of implementation may be combined with in-depth qualitative data to provide detailed understandings of intervention functioning on a small scale" (Moore et al., 2015, p. 6). Critical realists accept that multiple ways of seeking the truth may be useful and even necessary (Archer, 2016; Sayer, 2000): in the memorable phrase of Van Belle et al. (2016), realist research is "methodologically promiscuous" (p. 2). Greene et al. (2001) recommended that critical realist research should use mixed methods in order to provide the "lens of both generality and particularity, both objectivity and subjectivity, both patterned regularities and idiosyncratic stories" (Greene et al., 2001, p. 29). Maxwell (2012) argued that mixed methods can be used both for triangulation of findings and for "generating *divergent* perspectives, deepening rather than simply confirming our understanding" (p.66). While endorsing methodological pluralism, Archer and colleagues (2016) also noted that critical realism's judgemental rationality requires researchers to adjudicate between different accounts of reality and whether the knowledge claims are warranted.

Danermark et al. (2002) rejected some uses to which mixed methods may be put, seeing the use of qualitative methods purely as an exploratory step, before quantitative methods are brought in to 'validate' a finding, as incompatible with a critical realist approach: "an empirical connection in itself cannot identify the active mechanism or mechanisms, nor does it contribute to any profounder information about the interaction of the forces behind an observed pattern" (2002, p. 151). The MRC evaluation guidance arguably falls into this empirical "epistemic fallacy" (Bhaskar, 2008), by suggesting that at the post-pilot stage of evaluating effectiveness, quantitative measures may be collected to test hypothesised pathways (Moore et al., 2015).

## 2.4.2 Realist techniques

Bhaskar described the basic principle of critical realist data analysis: "theoretical explanation proceeds by description of significant features, retroduction to possible causes, elimination of alternatives and identification of the generative mechanism or causal structure at work" (1998, p. xviiii). Retroduction is a conceptual method used to identify underlying causal mechanisms, in order

to devise an explanatory theory that is the best fit with the observed data (Clark et al., 2008; McEvoy & Richards, 2003; Sayer, 1992). Retroduction uses both inductive and deductive reasoning in an iterative process between empirical data and theory, to answer the question "What properties must exist for X to exist and to be what X is? Or, to put it more briefly: What makes X possible?" (Danermark et al., 2002, p. 97). Data are collected to test the initial theory (deductive reasoning); where the data are inconsistent with the theory, these data are used to generate new theory (inductive reasoning); this new theory is then tested by the collection of more data (Astbury & Leeuw, 2010; Wong et al., 2017).

As well deductive and inductive logic, retroduction uses abduction in the form of the researcher's own 'hunches' and creative insights (Jagosh, 2020). Abduction, as a knowledge-extending form of inference that is distinct from both induction and deduction, derives originally from the theoretical work of Peirce (1938). It is the creative and necessarily provisional act of trying to find meaning-creating rules that explain unexpected facts (Reichertz, 2007). Jagosh (2020) described retroduction as the ontological side and abduction of the epistemological side of the same proverbial coin: "Whereas retroduction is inference to theorize and test hidden mechanisms, abduction is the inventive thinking required to imagine the existence of such mechanisms" (2020, p. 122). Specific techniques recommended by Danermark et al. (2002) included comparing cases, using counterfactual reasoning and considering outlying cases.

The research also drew on two techniques that have been developed more extensively in realist evaluation (Wong et al., 2017): realist interviewing, and coding evidence for C-M-O configurations, described in Chapter 6. Although it was not appropriate to *only* use a realist approach to interviewing (as discussed in section 2.2.5 above), the conceptual-focusing and teaching-learning functions were used, characterised by Pawson as "I'll show you my theory if you show me yours" (1996, p. 307).

#### 2.4.3 **Grounded Theory techniques**

Grounded Theory is a methodology devised to support the development of middle range sociological theory based on research data. In its original formulation by Glaser and Strauss (1967), it offered the first systematic guidelines for qualitative data collection and analysis, describing the researcher's role as 'discovering' theory about objective reality, unencumbered by preconceived theoretical frameworks. Strauss, with co-author Corbin, later acknowledged that the original description of Grounded Theory as an inductive methodology had been overplayed (Strauss & Corbin, 1994). They recommended that existing theoretical knowledge be used to formulate initial interview questions and to guide data analysis (Corbin & Strauss, 2015). A 'second generation' of grounded theorists has

continued to develop the methodology, freed from its original epistemological assumptions. In particular Charmaz, Clarke and Bryant have (separately) developed a constructivist version in which theory is understood to be actively constructed from the data; they characterise Grounded Theory as intrinsically abductive, with existing knowledge and theory used reflexively (Bryant, 2017; Charmaz, 2008; Clarke, 2005).

The compatibility between Grounded Theory and critical realism has been challenged by those who see Grounded Theory as inherently empiricist and inductive (Danermark et al., 2002; Fletcher, 2017), and defended by those who point to its more recent abductive emphasis and analytic engagement with existing theory (Hoddy, 2018; Oliver, 2012). There remains a key divergence: the purpose of Grounded Theory is to construct a theory that can "generate hypotheses and make explicit predictions" (Charmaz, 2008, p. 108), but for critical realists, theory in an open system with a stratified ontology can only be explanatory, not predictive (Bhaskar, 2008). Despite this philosophical difference, Oliver (2012) argued that some key techniques developed by grounded theorists are useful in a critical realist study, because Grounded Theory "is founded on the requirement to abandon preconceptions in the pursuit of intellectual leads" (p. 378) and these techniques effectively operationalise critical realism's commitment to knowledge as tentative. This research therefore used the Grounded Theory techniques of theoretical sampling, open coding as a separate stage from theoretical coding, constant comparison, and writing reflective memos (Corbin & Strauss, 2015; Glaser & Strauss, 1967), described in Chapter 6.

## 2.4.4 **Quality**

#### 2.4.4.1 **Quality in traditional mixed methods research**

Quantitative and qualitative methodologies have different vocabularies and techniques concerning the assessment of quality and trustworthiness of research inferences. Teddlie and Tashakkori (2009) proposed a framework for inference quality in mixed methods that primarily mirrored those of the qualitative and quantitative traditions as appropriate, but added a stage of integrative efficacy, which considers whether the inferences from each strand of the research have been integrated into the meta-inferences, and any inconsistencies adequately explored and theorised.

In quantitative research, *internal validity* describes the extent to which causal conclusions are warranted (through the apt design of the study to avoid confounding variables and bias), and *external validity* describes the extent to which the conclusions can be generalised to other people or situations (through appropriate sampling and high retention). *Reliability* describes the consistency of findings (over time or between those using the measures), and *objectivity* describes the neutrality of the researcher as an observer who does not influence the findings.

In qualitative research, there have been extensive debates about whether, and how, to assess quality (Spencer et al., 2003). Lincoln and Guba (1985) initially proposed four techniques that are intended to be analogous to those of quantitative research, although embedded in a constructivist perspective. *Credibility* (cf. internal validity) describes the extent to which the researcher's conclusions are true, achieved through techniques such as checking findings with participants; triangulation with other data sources, researchers or methods; and attention to negative cases and alternative explanations. *Transferability* (cf. external validity) describes the extent to which the conclusions might be relevant in another setting, achieved by the researcher providing detailed description of the participants and context so readers can draw inferences about generalisation. *Dependability* (cf. reliability) concerns the process of the inquiry and the ability of the researcher to yield consistent results, by documenting the methods, decisions and reflexivity. *Confirmability* (cf. objectivity) requires that the inferences are properly supported by the data, demonstrated by using illustrative quotations from a wide range of participants. Although frequently cited, these qualitative criteria have also been extensively debated, and cannot be seen as normative for all qualitative research (Whittemore et al., 2001).

Many attempts have subsequently been made to devise detailed frameworks of quality criteria to assess qualitative research, and Munthe-Kaas et al. (2019) found 102 qualitative critical appraisal tools. These checklists have attracted a sustained philosophical and practical critique, on the grounds of inconsistency, methodological incoherence (e.g. combining items from incompatible philosophical approaches), and (ironically) a lack of critical engagement with the questions at stake: "none of the identified critical appraisal tools appear to be based on empirical evidence or clear hypotheses related to how specific elements of qualitative study design or conduct influence the trustworthiness of study findings" (Buus & Agdal, 2013; Buus & Perron, 2020; Munthe-Kaas et al., 2019, p. 10; Sandelowski, 2015). There also has been a strong challenge to the notion that criteria based on specific procedures (no matter how numerous) can guarantee quality of data or conclusions: "Validity is not a commodity that can be purchased with techniques... Rather, validity is like integrity, character and quality, to be assessed relative to purposes and circumstances" (Barbour, 2001; Brinberg & McGrath, 1985, p. 13; Sandelowski, 2015).

#### 2.4.4.2 Quality in critical realist research

Maxwell (2012) cautioned that from a realist perspective, the challenge is to identify a way to make validity judgements other than by the use of specific procedures, given the intrinsically fallible nature of human understandings of real phenomena. Specific procedures are useful, but their contribution to validity depends not on their correct use per se, but on the conclusions which they are used to generate and the potential validity threats to those conclusions. Maxwell's proposed

answer was grounded in the realist requirement to search out and evaluate counter-examples and alternative interpretations to the developing theory: "It involves identifying the plausible alternatives to the proposed explanation, interpretation or conclusion, deciding what data exist or could be obtained that would count as evidence for or against this conclusion or the plausible alternatives, and then collecting or examining those data to determine the plausibility of these possible conclusions" (2012, p. 131). This approach was essential in the context of perinatal mental health peer support, where there are at least three possible alternative causes for changes in mood during the time peer support was used: spontaneous resolution of perinatal mental health difficulties (see section 1.1.2), use of psychological therapy or medication, and positive or negative life events.

Because of the close affinity between theory-based evaluation and realist evaluation, this research has also been guided by the quality and reporting standards for realist evaluations published by the RAMESES II project team (Wong et al., 2017; Wong et al., 2016). These give detailed guidance on achieving quality through the application of realist principles across all aspects of the evaluation, including: defining the purpose of the evaluation in realist terms; the application of the principle of generative causation throughout; the construction and refining of realist programme theories; coherent evaluation design that tests multiple aspects of programme theory and enables alternative explanations to be investigated; data collection methods that are suitable for the realist endeavour; taking a retroductive approach to overall data analysis and using analytic processes which are consistent with generative causation; and applying realist logic to iterative development and refinement of theory, identifying relationships between contexts, mechanisms and outcomes.

## 2.5 Chapter summary

Critical realism is a philosophical paradigm based on ontological depth and generative causation. Applied to evaluation research, it focuses attention on the mechanisms of change within a social programme that may be triggered in specific contexts to produce outcomes. It is used in this research as the underpinning for a theory-based process evaluation of the Parents in Mind pilot programme, a 'clear box' evaluation that explores what works in perinatal mental health peer support, for whom, in what circumstances, in what respects, and why.

A realist literature review was chosen to complement the primary research and inform the initial theory of change. The primary research used mixed methods, as recommended by the MRC and expected in critical realist research. The realist mode of inference (retroduction) was used throughout, along with the realist techniques of coding for C-M-O configurations and realist

interviewing. Additional techniques were derived from Grounded Theory, which furnishes robust procedures that can be used to support a critical realist enquiry. This research was guided by the general quality principles applying to mixed methods research as well as those specifically pertinent to realist research.

# **3 Realist Review - Methods**

## **Chapter overview**

This chapter describes the methods used in a realist review of community-based perinatal mental health peer support programmes, offering support either in groups or one-to-one from trained peer supporters with their own experience of perinatal mental health difficulties. It explains how the review explores the different contexts, mechanisms and outcomes involved, guided by the realist synthesis question *"What is it about community-based perinatal mental health peer support that works, for whom, in what circumstances, in what respects, and why?"* It describes the stages of realist review: exploratory searching, development of an initial theoretical model, searching for empirical studies, quality appraisal and data extraction, context-mechanism-outcome analysis, and the development of a final theoretical model.

## 3.1 Review aim and question

The aim of this review was to synthesise the literature on perinatal mental health peer support programmes outside mental health services, in a format that would support the development of a theory of change for the Parents in Mind programme. The overall question for this realist review was: "What is it (M) about community-based perinatal mental health peer support that works (O), for whom (C), in what circumstances (C), in what respects (O) and why (M)?"

## 3.2 Objectives

The objectives of the review were:

- To explore the **mechanisms** underlying the <u>take-up</u> of perinatal mental health peer support by mothers.
- To explore the **positive and negative mechanisms** underlying the <u>impact</u> of perinatal mental health peer support on mothers using it.
- To identify the **positive and negative outcomes** linked to use of perinatal mental health peer support.
- To identify the **contexts** in which these mechanisms operate and for whom they operate to produce outcomes.
- To create a **theoretical model** linking contexts, mechanisms and outcomes.

## 3.3 Rationale for focus of review

This review focused on community-based perinatal mental health peer support from trained peers and/or in groups where the facilitator was not a mental health professional and the sole aim was the

opportunity for peer support. This was in order to focus on programmes that had comparable features to Parents in Mind, and to understand the specifically 'peer' aspect of the support.

It was originally intended to include impacts on volunteer peer supporters, because they may be considered reciprocal beneficiaries of peer support programmes, and also because their experiences are part of the theory of change in the primary research. Given the size and complexity of the additional literature on volunteering and the finite time available, it became apparent that this breadth of review would be at the expense of its overall depth, so it was decided to focus on the mothers using peer support. This decision was in keeping with the RAMESES guidelines that the objectives of a review will be progressively focused during the review itself (Wong et al., 2013). Evidence about the experiences of peer volunteers was, however, included if it contained information relevant to how their programme worked for mothers.

## 3.4 Steps of realist review

A realist review has an established sequence of steps (Wong et al., 2013), shown in Figure 3. The actual process of realist review is fluid, iterative and non-linear, and "feeds on fresh evidence as it unfolds" (Pawson, 2006b, p. 11). In keeping with the RAMESES guidelines (Wong et al., 2013), this chapter presents the review in an orderly sequence.

## Figure 3 Steps in the realist review simplified to appear linear



## 3.5 Exploratory searching

The first stage of searching was exploratory. The sequencing of the two stages of realist review searches and the primary research was shown in Figure 1.

## 3.5.1 Aims of exploratory searching

The exploratory searching had four aims:

- (1) To understand the policy background and current debates about peer support. These have been included in Chapter 1.
- (2) To identify third sector organisations currently offering perinatal mental health peer support in the UK, to be contacted for information during the search for empirical studies.
- (3) To identify candidate contextual factors. These are reported in Chapter 4, section 4.2.

(4) To identify candidate mechanisms and outcomes. These are reported in Chapter 4, section4.3.

## 3.5.2 **Process of exploratory searching**

Pawson et al. (2005) describe this stage of the review as "scaveng[ing] ideas". The exploratory searching was therefore carried out using a variety of strategies:

- Resources in the Maternal Mental Health Alliance's resource hub, and member organisations providing peer support (<u>https://maternalmentalhealthalliance.org</u>)
- (2) Searches of policy and practice websites, using the term "perinatal mental health": (<u>https://www.england.nhs.uk</u>, <u>https://www.gov.uk</u>, <u>https://fingertips.phe.org.uk/profile-group/mental-health/profile/perinatal-mental-health</u>, <u>https://www.rcpsych.ac.uk/</u>, <u>www.nice.org.uk</u>).
- (3) A search of Medline and Google Scholar using search terms combining 'peer support', 'selfhelp', 'support group' and 'mental health/illness'.
- (4) A search of Medline and Google Scholar using search terms combining 'perinatal/antenatal/postnatal', 'mental health/illness' and 'experiences'.
- (5) Forward and backward citation searching from key texts.
- (6) Discussion and debate with providers of third sector peer support at conferences: Society for Reproductive and Infant Psychology 2016-19; Power of Volunteering During Pregnancy, Birth & Beyond 2017; Royal College of Psychiatrists, Perinatal Quality Network Annual Forum 2018; Maternal Mental Health Alliance 2018; and Celebrate Volunteering in Pregnancy, Birth & Beyond 2020.
- (7) Discussion with commissioners and providers of peer support at the Maternal Mental Health Alliance's 'Mums and Babies in Mind' masterclasses 2018-9.
- (8) Google searches for additional third sector organisations, using the combined terms'perinatal/postnatal/maternal', 'mental health/depression', and 'support group/self-help'.

The exploratory searching did *not* include primary studies of perinatal mental health peer support, as these were the object of the second search phase (the search for empirical studies). This phase did, however, draw on insights gained during three pieces of work I carried out separately from this doctoral research:

(1) A rapid review of the evidence on volunteering and early childhood outcomes, carried out in 2015-16 with colleagues from the Institute for Voluntary Action Research, Parents 1<sup>st</sup> and the University of Bedfordshire, to support the development of volunteer and peer support in the A Better Start programme (McLeish et al., 2016a).

- (2) A realist evaluation of five programmes offering volunteer doula support in England, carried out in 2013-15 with colleagues from the University of York (Darwin et al., 2017; McLeish et al., 2016b; Spiby et al., 2015; Spiby et al., 2016).
- (3) Qualitative research based on interviews with 72 volunteers and 63 supported mothers in 14 third sector perinatal support programmes, carried out 2013-19 as part of the National Institute for Health Research (NIHR) Policy Research Programme, conducted through the Policy Research Unit in Maternal Health and Care (McLeish & Redshaw, 2015, 2016, 2017a, 2017b, 2017c).

## 3.6 Initial theoretical model

The results of the exploratory search, combined with "conjectures … ideas… and hunches" (Pawson, 2006b, p. 2) were used to construct an initial theoretical model for perinatal mental health peer support programmes, linking hypothesised contexts, mechanisms and outcomes. Each programme theory was an individual C-M-O configuration. The retroductive realist question 'what must be true for this to be the case?' was used to theorise how partial C-M-O configurations could be developed more fully, working backwards from effects to the conditions that would be necessary for those effects to be produced (Jagosh, 2020).

#### **3.7 Search for empirical studies**

The second stage of searching was for empirical studies of perinatal mental health peer support interventions. In a realist review, the search for empirical evidence to test the initial theoretical model is purposively rather than methodologically driven and can draw on both academic and nonacademic literature (Pawson, 2006b). This review therefore included qualitative, quantitative and mixed methods studies, and also literature generated by third sector peer support programmes in England.

#### 3.7.1 Search process

Searches were carried out in four databases, without date restrictions: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Scopus and PsychInfo, with the last search conducted in March 2020.

Search terms combined words related to 'perinatal', words related to 'mental health', and words related to 'peer support' or 'support group':

Perinatal OR Pregnan\* OR Antenatal\* OR Postnatal\* OR Postpartum OR Maternal OR Parent\* OR Mother\*

AND Mental health OR Mental illness OR Emotional\* OR Wellbeing\* OR Depress\* OR Anxiety OR Anxious OR PND OR OCD OR Psychosis

AND Peer support\* OR Peer work\* OR Volunteer\* OR Peer\* or Community run organi\* OR self-help OR self help OR support group OR consumer-provider OR consumer

A search was also carried out in the British Library E-theses Online service (EthOS). Discussion with the lead author of one study following a conference presentation (Sembi et al., 2015) indicated that there would be material relevant to the review that was not in the published paper, so a search of a university repository was carried out to locate her subsequent doctoral thesis (Sembi, 2018). Backward citations in included papers were then searched. In addition to these searches, 11 third sector organisations were contacted by email to request project reports, evaluations or other literature.

Although Pawson et al. (2005) refer to the possibility of applying the test of saturation to decide when to stop searching, they also note that it is rare to find an over-abundance of empirical studies. This search was therefore based on the principle of including all studies that met the criteria and for which full texts were available.

## 3.7.2 Inclusion and exclusion criteria

The inclusion and exclusion criteria for the empirical studies are shown in Table 2.

## Table 2 Selection criteria for empirical studies

	Inclusion criteria	Exclusion criteria
Type of study	Empirical study of participant experiences, outcomes or process.	Review article
Methodology	Any	
Population	Women experiencing any type and level of perinatal mental health difficulties, diagnosed or self- identified.	<ul> <li>Women outside the perinatal period* when they received peer support.</li> <li>Women who did not identify themselves as having any perinatal mental health difficulty.</li> </ul>
Intervention	<ul> <li>Interventions offering peer support for perinatal mental health difficulties, face-to-face or by telephone, including:</li> <li>One-to-one peer support from trained peers (with personal experience of perinatal mental health difficulties).</li> <li>Peer support groups facilitated by peers or non-peers.</li> </ul>	<ul> <li>Interventions combining psychological therapy and peer support.</li> <li>Groups facilitated by a mental health professional.</li> <li>Peer support interventions not primarily focused on perinatal mental health difficulties (e.g. a parent and baby group open to anyone, a breastfeeding support group).</li> <li>Interventions aimed at preventing perinatal mental health difficulties.</li> <li>Interventions primarily offering peer education.</li> <li>Interventions based on internet chat forums.</li> </ul>
Setting	<ul> <li>Interventions based in the community.</li> <li>Interventions in any country.</li> </ul>	<ul> <li>Peer support offered as part of a mental health service.</li> <li>Peer support not in community settings (e.g. a neonatal intensive care unit).</li> </ul>

\*For the purpose of this review, the perinatal period was defined as pregnancy and the two years after birth, to mirror the criteria used by Parents in Mind.

# 3.8 Appraisal of documents

There are no standard itemised quality criteria for use in a realist review. Pawson (2006a, 2006b) argued against the use of quality appraisal checklists, because these are designed to be applied to whole studies and it is not normally appropriate to treat the study itself as the unit of analysis:

"Studies that are technically deficient in some overall sense may, if inspected closely, still provide trustworthy nuggets of information to contribute to the overall synthesis" (Pawson, 2006b, p. 18). Quality assessment therefore does not take place before data extraction, but can only be done as part of the process of synthesis (Pawson, 2006a, 2006b). The RAMESES standards include two considerations for appraising any section of a document:

- Relevance whether it can contribute to theory building and/or testing; and
- Rigour whether the method used to generate that particular piece of data is credible and trustworthy (Wong et al., 2013), which may be informed by quality standards appropriate to the specific type of research.

This review has therefore not used quality appraisal checklists applied to whole documents to determine the inclusion of a document. Instead, each included document was read closely and critically as part of the data extraction process. For research or evaluation studies the appropriate quality criteria from the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) were used to guide an overall assessment of methodological quality. This tool was chosen to be usable across the range of methodologies of included studies; the results of this assessment are presented in Appendix B.

Each part of each document was next considered individually, first for its relevance to this review – whether it contained any information relevant to the testing of the initial theoretical model or to any unanticipated C-M-O configurations. Secondly, the assessment of rigour depended on the use to which the piece of data extracted was to be put, consistent with critical realism's judgemental rationality about knowledge claims (Archer et al., 2016). Data relevant to contexts, mechanisms and proximate outcomes were judged according to how reliably the specific piece of information was generated, mindful of the strengths and weaknesses of the whole study (the MMAT assessment). For mechanisms and outcomes, most weight was given to points supported by direct quotation from mothers who had received peer support, and validated questionnaires that asked about their *attribution* to peer support of any improvements. For contexts, equal weight was given to the words of research participants and to researchers' reflections on setting up and running peer support interventions.

Evaluations of perinatal peer support and volunteer programmes commonly use mental health questionnaires as part of before/after methodology (Thomson & McLeish, 2018). Changes in mental health scores are often uncritically reported as evidence of impact on maternal mental health, without any investigation of alternative explanations which might enable programmes to make credible causal claims about their impact on outcomes, in the absence of experimental design

(Mayne, 2001). Therefore only experimental and quasi-experimental studies were relied on for claims about the impact of peer support on measurable symptoms of depression and anxiety. The credibility of these claims was judged by considering the quality of the whole study, guided by the MMAT assessment.

## 3.9 Data extraction

The following information was recorded in an Excel spreadsheet for each document:

- Study type and methods.
- Contextual factors identified during data extraction personal characteristics of mothers and peer supporters, the programme's setting, whether peers were involved in creating the programme, the relationship with health services, the cultural norms described in relation to motherhood and mental health.
- Aspects of the intervention group or one-to-one; face-to-face or by telephone; how often; for how long; whether unstructured or structured; referral of mothers; recruitment, training and support of volunteers; retention of volunteers and mothers.
- Positive and negative mechanisms identified during data extraction.
- Outcomes reported.
- Middle range theories explicitly used by the authors.
- Quality assessment addressing relevance and rigour.

There was no expectation that authors would themselves have described their findings in realist terms. Personal correspondence with the author or programme leader was used to clarify factual information where necessary.

## 3.10 Context-mechanism-outcome analysis

To facilitate detailed cross-study analysis, the texts of the papers were entered into NVIVO software. Nodes were created for the draft programme theories (C-M-O configurations) from the initial theoretical model. Papers were coded in an iterative process as described by Dalkin et al. (2021). Deductive coding was based on the original draft programme theory nodes. New nodes were created for inductive coding where the analysis suggested a new C-M-O configuration not anticipated in the initial theoretical model. Further new nodes were created to represent partial programme theories, for example, a context and mechanism but no outcome, or a mechanism and outcome but no context.

## 3.11 Creation of final theoretical model

Each programme theory in the initial theoretical model was then tested against the evidence drawn from the included studies, using the results of the C-M-O analysis. As for the initial theoretical model, the retroductive realist question 'what must be true for this to be the case?' was used to theorise how partial C-M-O configurations could be developed more fully (Jagosh, 2020).

Additional columns were added to the initial theoretical model to record (1) all the papers that provided evidence either supporting or countering the theory, and (2) supporting quotations from the papers. Where the C-M-O analysis indicated a new programme theory not anticipated in the initial theoretical model, or a refinement to an existing theory, this was added to the model. The final theoretical model was thus a combination of those parts of the initial theoretical model that were supported by the C-M-O analysis, and new programme theories identified through the C-M-O analysis.

## 3.12 Chapter summary

A realist review of community-based mental health peer support was carried out to answer the question 'What is it about community-based perinatal mental health peer support that works, for whom, in what circumstances, in what respects, and why?' The methods described in this chapter followed a series of steps designed to first hypothesise programme theories (C-M-O configurations), and then to test this initial theoretical model against evidence from empirical studies of perinatal mental health peer support. The results of this testing were used to construct a final theoretical model.

The next two chapters present the results of the realist review. Chapter 4 presents the results of the exploratory searching: the candidate contextual factors, mechanisms and outcomes used to construct the initial theoretical model. Chapter 5 presents the results of the empirical searching and the testing of the initial theoretical model to create a final theoretical model.

# 4 Realist Review – Results, Part 1

## **Chapter overview**

This chapter is part 1 of the findings of the realist review of community-based perinatal mental health peer support, presenting the narrative results of the exploratory searching from which the initial theoretical model was constructed. It describes contextual factors that could affect take-up and the mechanisms of peer support, relevant to the review questions 'for whom, and in what circumstances', which were primarily drawn from the qualitative literature on women's experiences of perinatal mental health difficulties. It then describes candidate mechanisms and outcomes relevant to the review questions 'what is it ... that works ... in what respects and why?', which were mainly derived from middle range psychological theories of mental health peer support, and empirical studies of non-perinatal mental health peer support.

## 4.1 Chapter introduction

The results of the exploratory searching relevant to contexts, mechanism and outcomes, combined with retroductive theorising about these findings, were used to develop an initial theoretical model. The term 'candidate' is used to indicate that these contexts, mechanisms and outcomes were hypotheses at this stage, before the initial theoretical model was tested against empirical evidence from perinatal peer support studies.

To avoid repetition, the whole initial theoretical model (showing C-M-O configurations) is not presented separately. Instead, it has been incorporated into the final theoretical model, which is presented in Chapter 5 (Table 5, Table 6 and Table 7).

## 4.2 Candidate contextual factors

## 4.2.1 Evidence sources

This section reports on candidate contextual factors *('for whom, and in what circumstances?'*) identified through exploratory searching: those factors that could cause mechanisms to activate (or not). The evidence used for this part of the review was mainly from qualitative studies about maternal mental health, the majority of which focused on postnatal depression. The evidence comprised 42 qualitative studies, three studies based on questionnaires, three mixed methods studies, nine reviews (of which four were qualitative meta-syntheses), five theoretical books or articles, and six websites. Of the 48 primary studies, 31 were from the UK, 10 from the USA and

Canada, four from Australia, two from Scandinavia, and one was multi-country. Details of these sources are shown in Appendix A.

## 4.2.2 Summary and labelling of contextual factors

The contextual factors described in this section are grouped at two levels. Those labelled 'C-Society' are macro-level or meso-level factors (e.g. socio-cultural values or the organisation of local services). Those labelled 'C-Individual' are micro-level factors (e.g. mothers' personal characteristics and beliefs).

A summary of the candidate contextual factors identified is shown in Table 3, and this is followed by a narrative account of these factors and the sources from which they were identified, with related society/individual factors grouped together in each subsection.

Label	Potential contextual factor affecting take-up and/or impact	Heading in text	
C-Society 1	Cultural narratives of idealised motherhood	The 'myth' of motherhood and stigma of mental illness	
C-Society 2	Stigma of mental illness		
C-Society 3	Expectation that new mothers will meet social support needs through other new parents	Withdrawal from other mothers	
C-Society 4	Primary health professionals have limited training on perinatal mental health difficulties and limited time	Avoiding professional intervention	
C-Society 5	Different conceptions of mental health difficulties and appropriate response	Diverse conceptions of perinatal mental health difficulties	
C-Society 6	Public health campaigns promote message 'it's good to talk', but there are differences in the acceptability of talking to outsiders	It's good to talk: accepting the merits of talking to outsiders	
C-Society 7	Limited access to perinatal mental health support, including long waiting lists	Peer support as a poor relation to professional support	
C-Society 8	Social norm that mother is primarily responsible for meeting baby's needs alongside domestic responsibilities and other work	Lack of time and money	
C-Society 9	Pool of suitable potential volunteers exists in local community	Suitable pool of potential volunteers available	
C-Individual 1	Mother labels herself negatively as a uniquely abnormal 'bad' mother	The 'myth' of motherhood and stigma of mental illness	
C-Individual 2	Mother hides feelings from partner, family & friends and cannot meet needs for authenticity in relationships	Withdrawal from family and friends	
C-Individual 3	Mother lacks a social network		

## **Table 3** Candidate contextual factors showing labelling

Label	Potential contextual factor affecting take-up and/or impact	Heading in text
C-Individual 4	Mother avoids new parent groups as these make her feel worse	Withdrawal from other mothers
C-Individual 5	Mother conceals symptoms from professionals – fear of judgment, consequences, lack of understanding / empathy	Avoiding professional intervention
C-Individual 6	Mother trusts health professionals	Referral pathways
C-Individual 7	Mother has a personal conception of cause and meaning of perinatal mental health difficulties	Diverse conceptions of perinatal mental health difficulties
C-Individual 8	Mother believes it is useful and acceptable to talk about mental health difficulties	It's good to talk: accepting the merits of talking to outsiders
C-Individual 9	Mother has a preference for cultural homogeneity or heterogeneity	Cultural homogeneity or heterogeneity
C-Individual 10	Mother actually wants psychological therapy	Peer support as a poor relation to professional support
C-Individual 11	Mother has resources of time and/or money to invest in meeting her own needs	Lack of time and money
C-Individual 12	Mother has low social confidence	Social confidence
C-Individual 13	Mother is sufficiently well to give as well as receive peer support	Nature and severity of the mental health difficulty
C-Individual 14	Mother has low self-esteem and low internal locus of control	Self-esteem and internal locus of control

## 4.2.3 The 'myth' of motherhood and stigma of mental illness

In many cultures there is a prevailing narrative or 'myth' of idealised, contented, devoted, and instinctive pregnancy and motherhood **(C-Society 1)**, alongside a strong stigmatisation of mental illness **(C-Society 2)** (Hall, 1998; Hays, 1996; Knudson-Martin & Silverstein, 2009; Schmied et al., 2017; Stoppard, 2000). Qualitative researchers have explored mothers' subjective experiences of perinatal mental health difficulties, mainly postnatal depression. They have highlighted how some mothers experience a painful dissonance between what they expect and believe to be emotionally and practically 'normal', and their experienced reality of pregnancy and motherhood **(C-Individual 1)**. This includes ambivalent feelings about the pregnancy; difficulties caring for their unsettled baby; problems with breastfeeding; and negative postnatal feelings such as loss, anger, grief, anxiety and sadness (Ali, 2018; Beck, 2002; Bilszta et al., 2010; Coates et al., 2014; Evans et al., 2017; Haga et al., 2012; Highet et al., 2014; Mauthner, 1995; Schmied et al., 2017; Staneva & Wigginton, 2018).

Mothers may become intensely self-critical and believe that they are abnormal 'bad' mothers who have 'failed', leading to guilt and shame, which contribute to low self-esteem (Beck, 1993; Bennett et al., 2007; Bilszta et al., 2010; Knudson-Martin & Silverstein, 2009; Mauthner, 1995). Shame and guilt may be especially strong if mothers have thoughts of wanting to harm their baby (Choi et al., 2005; Ugarriza, 2002). The perceived and internalised stigma of having a mental health difficulty can intertwine with the perceived and internalised stigma of being a 'bad' mother in ways which are mutually reinforcing, and the solutions offered to mental health difficulties (such as taking antidepressants) can intensify a negative maternal self-image (Bilszta et al., 2010; Patel et al., 2013; Raymond, 2009). It may be the downwards spiral from chronic tiredess and mothering difficulties into shame and despair that distinguishes postnatal depression from milder negative feelings (Knudson-Martin & Silverstein, 2009), a process described by one of Mauthner's respondents as "feeling low and feeling really bad about feeling low" (1999, p. 159). Believing that they are *uniquely* failing and that no one else can understand them, these mothers may withdraw from social contact into lonely silence (Beck, 1993; Jones et al., 2014; Mauthner, 1995).

There may be personality and cultural components to this negative self-labelling, and the consequent damage to self-concept. The discrepancy between normative expectations of motherhood and reality may be particularly acute for mothers with rigid or perfectionist expectations of themselves, or those who have a higher need for mastery and control, or those whose self-image is built on being a strong, autonomous and capable woman (Edge & Rogers, 2005; Haga et al., 2012; Knudson-Martin & Silverstein, 2009; Scrandis, 2005; Tammentie et al., 2004). The low income, ethnic minority mothers interviewed by Abrams and Curran (2011) in the United States were able to maintain a positive maternal identity that co-existed with their symptoms of depression; they compared themselves favourably to real or imagined 'other' disadvantaged mothers who they believed were stereotypically neglectful. The authors suggested that this enabled these mothers to resist the loss of self which was reported in studies of mainly White, middle class mothers (Beck, 2002), and to assert an authentic inner self that was separate from their depression, which they framed as an external force. In some cultures, self-comparison against a supposed normative experience may be completely absent - Currer (1984) noted that for her Pathan interviewees in Bradford, "There seemed to be a lack of the habit of comparing oneself with an imaginary other" (p.73).

#### 4.2.4 Withdrawal from family and friends

Mothers may conceal their feelings from partner, family and friends (**C-Individual 2**) to avoid being judged by them or burdening them; or they may find partner, family and friends unable to understand their feelings; or they may feel pressurised to deny or conceal their feelings (Bennett et

al., 2007; Bilszta et al., 2010; Franks et al., 2017; McIntosh, 1993; McLeish & Redshaw, 2017b; Patel et al., 2013; Schmied et al., 2017; Staneva & Wigginton, 2018). This cuts them off from being able to meet their needs for a sense of belonging and authentic relationships within their existing social network (Bennett et al., 2007; Mauthner, 1995). Alternatively mothers may have little or no social network to turn to **(C-Individual 3)**, for example due to migration or homelessness (McLeish & Redshaw, 2017b).

### 4.2.5 Withdrawal from other mothers

Having a baby disrupts patterns of social relationships, particularly for mothers who have previously been in work or education. There is an expectation that new mothers will meet their needs for social contact by socialising with other new mothers **(C-Society 3)**; and talking to other mothers is an important way in which new mothers evaluate themselves (Mauthner, 1995; Scrandis, 2005). However, mothers with perinatal mental health difficulties may avoid others who they perceive as coping better **(C-Individual 4)**, because they find it demoralising to be reminded of other mothers' apparent happiness, and fear being judged as 'bad' mothers by those apparently 'good' mothers (Beck, 1993; Bennett et al., 2007; Mauthner, 1995; Scrandis, 2005; Tammentie et al., 2004). Alternatively they may continue to socialise while hiding their authentic feelings behind a pretense of happiness (Bennett et al., 2007). Either strategy cuts them off from being able to meet their needs for a sense of belonging and authentic relationships within a motherhood-based social network (Bennett et al., 2007; Mauthner, 1995). In a vicious circle, the withdrawal and self-silencing practised by mothers with mental health difficulties perpetuates the culture among mothers where postnatal depression is not openly acknowledged (Jones et al., 2014a; Mauthner, 1995).

#### 4.2.6 Avoiding professional intervention

Primary health professionals receive limited training on perinatal mental health difficulties and many are not skilled in responding to them **(C-Society 4)** (Bayrampour et al., 2018; Khan, 2015). Some mothers actively avoid professional diagnosis and intervention by concealing their symptoms from health professionals **(C-Individual 5)**, often because of fear of being judged and labelled, belief that child protection services will take their baby away, or fear of an abusive psychiatric system (Edge & MacKian, 2010; Edge & Rogers, 2005; Franks et al., 2017; Iles & Pote, 2015; McIntosh, 1993; Morrow et al., 2008; Patel et al., 2013; Staneva & Wigginton, 2018). Some mothers, who receive reassurances that what they are experiencing is a 'normal' reaction to motherhood, interpret this as denying their distress, particularly if the reassurance comes from a health professional without personal experience (Edge & Rogers, 2005; Knudson-Martin & Silverstein, 2009; McIntosh, 1993; Royal College of Obstericians and Gynaecologists, 2017). Peer support programmes that offer self-

referral may enable access to mothers who wish to avoid professional involvement (researcher's inference).

#### 4.2.7 Referral pathways

Where a mother trusts health professionals and discloses her mental health difficulties to them, this may be an important referral route to peer support. Referrals are most likely when there is a good relationship between the peer support programme and local health professionals **(C- Individual 6)**, who understand its purpose and have easy ways to refer (McLeish et al., 2016a).

#### 4.2.8 **Diverse conceptions of perinatal mental health difficulties**

Kleinman et al. (1978) highlighted the importance of clinicians paying attention to a patient's own explanatory model - the subjective meanings they attach to their illness. Individual perceptions of illness may affect willingness to seek treatment or support (Baines & Wittkowski, 2013). There are a range of popular conceptualisations of the causes of perinatal mental health difficulties, reflecting ideas about mental health more generally (C-Society 5). Women's own beliefs about the nature and causes of their perinatal mental health difficulties may affect their beliefs about the utility of peer support as a solution (C-Individual 7). Some women embrace a medical diagnosis of their symptoms, and feel relieved and legitimised by this; others reject a pathological label, resenting the connotations of being 'mentally ill' when they can see good reasons for their own unhappiness (Edge & MacKian, 2010; Edge & Rogers, 2005; Iles & Pote, 2015; Mauthner, 1999; McIntosh, 1993; Nicolson, 1991; Patel et al., 2013; Staneva & Wigginton, 2018). Their personal explanations include: social circumstances (such as loneliness or the burdens of work), conflicted family relationships, the baby's temperament, difficulties breastfeeding, exhaustion, stressful life events, chronic stressors, their own personality, loss of control and identity, shame of feeling unhappy and incompetent at what is expected to be joyful and natural, hormonal or biochemical factors, and religious interpretations (Abrams & Curran, 2009; Ali, 2018; Baines et al., 2013; Coates et al., 2015; Edge & Rogers, 2005; Franks et al., 2017; Gardner et al., 2014; Highet et al., 2014; Knudson-Martin & Silverstein, 2009; McIntosh, 1993; Morrow et al., 2008; Nicolson, 1991; Oates et al., 2004; Patel et al., 2013; Schmied et al., 2017; Small et al., 1994; Ugarriza, 2002; Watson et al., 2019; Wittkowski et al., 2011). Mothers may not seek out peer support as a likely answer to their difficulties if they believe they have a medical illness or hormonal problem requiring a pharmaceutical solution (researcher's inference). Mothers who understand their distress as a response to the intolerable burden of social problems may not see the point in asking for outside help, unless that is practical support such as help with housework or baby care (McIntosh, 1993; Parvin et al., 2004; Templeton et al., 2003). Mothers who frame their distress within a religious context may believe that it should be managed by prayer or endurance (Parvin et al., 2004). The terminology that perinatal mental

health peer support programmes use to describe themselves may affect mothers' willingness to make use of the peer support. For example, programmes that affirm mothers' distress as "indeed a very real illness" (Juno, undated), may be most engaging for mothers who share this medical construction, while programmes that avoid explicit 'mental health' language may be more successful at attracting mothers who do not see their distress as illness (Billsborough et al., 2017).

Some researchers have suggested that women with lower socio-economic status and women from Black, Asian and minority ethnic communities may be particularly likely to have a social rather than a medical understanding of perinatal mental health difficulties, and that this may therefore reduce their engagement with services (Abrams & Curran, 2009; Edge & MacKian, 2010; McIntosh, 1993; Parvin et al., 2004). In their multi-centre study of perceptions of postnatal depression, Oates et al. (2004) found that the experience of morbid depression after birth was universally recognised but that the term 'postnatal depression' was not used by UK South Asians; and some of the UK South Asian mothers interviewed by Wittkowski et al. (2011) had no concept of 'postnatal depression' at all.

#### 4.2.9 It's good to talk: accepting the merits of talking to outsiders

Public health campaigns in England have vigorously promoted the mental health message 'it's good to talk' **(C-Society 6)** (Heads Together, undated; Young Minds, 2020). Irrespective of their beliefs about the causes and meaning of their perinatal mental health difficulties, mothers who accept this cultural narrative might be willing to use using peer support **(C-Individual 8)** (researcher's inference). However, even if a mother accepts that talking about her problems can be beneficial, there may be cultural differences in beliefs about the extent to which it is ever appropriate to seek help through talking with someone outside the family (Schmied et al., 2017). For example Edge and Rogers (2005) reported that their Black Caribbean interviewees in the UK described being brought up not to discuss their problems outside the home, but to conform to a 'Strong Black Woman' identity expressed by coping with adversity alone. Most of the Bangladeshi mothers interviewed by Parvin et al. (2004) in the UK believed that talking to someone outside the family would shame the family. Oates et al. (2004) likewise reported that their UK South Asian participants did not feel it was appropriate to seek external help for postnatal depression. In the context of depression more generally, it has been questioned whether the individualistic nature of Western talking therapies is relevant to women from a collectivist tradition (Burr & Chapman, 2004).

#### 4.2.10 Cultural homogeneity or heterogeneity

Some mothers from minority ethnic backgrounds feel more comfortable discussing their perinatal mental health with others from the same cultural or linguistic background, while others feel exposed in a group with people from their own community and worry about breaches of confidentiality **(C**-

**Individual 9)** (Edge & Rogers, 2005; Masood et al., 2015; McLeish & Redshaw, 2015; Parvin et al., 2004). A peer support programme may therefore be more attractive to some participants if it offers culturally homogenous groups or culturally matched peer supporters; and more attractive to other participants if it offers them the opportunity of peer support from people outside their community (Billsborough et al., 2017). Some people looking for support might prioritise shared background or identity over peer mental health experience (Faulkner et al., 2013).

#### 4.2.11 Peer support as a poor relation to professional support

There can be lengthy delays for pregnant women and new mothers who want to access professional mental health services (**C-Society 7**). In a large survey of mothers in 2017, two-fifths who were referred to mental health services had waited over four weeks for an initial assessment, and two-fifths had then waited over three months for a psychological intervention to begin (Royal College of Obstericians and Gynaecologists, 2017). Some mothers may want psychological therapy and turn to peer support while on the waiting list or having been turned down because they do not meet the service criteria (**C-Individual 10**). They may hope or expect that peer support will be similar to psychological therapy (researcher's inference). Some peer support organisations position their support as an alternative pathway for mothers who cannot get professional help, which may appeal to mothers unsuccessfully seeking professional help. For example peer-led charity Cocoon Family Support described how it filled a gap in service provision: "[The founder] found there was very little support available to those parents who were 'not quite ill enough' for the specialist mental health services. To this day, Cocoon works with those parents who are not receiving support from anyone else" (Cocoon, undated).

## 4.2.12 Lack of time and money

Lack of time and money may be obstacles for some mothers who want to get help with their perinatal mental health difficulties **(C-Individual 11)**, in the context of childcare and domestic responsibilities that disproportionately fall on mothers **(C-Society 8)** (Goodman, 2009; Schmied et al., 2017; Templeton et al., 2003). Support by telephone may help to overcome these obstacles, as may drop-in group support where there is no obligation to attend regularly (researcher's inference).

#### 4.2.13 Social confidence

Some mothers lack social confidence or have social anxiety **(C-Individual 12)**. They are less likely to be willing to attend any group, although they may feel safe talking in a one-to-one situation (McLeish & Redshaw, 2017b). Conversely, some mothers expect one-to-one support to be a dauntingly intense social obligation, and prefer a group (McLeish et al., 2016a). Peer support programmes that are able to offer mothers a choice of one-to-one or group support will therefore

meet the widest range of needs. Mothers may be more willing to be open about their difficulties if they are more self-confident, and also if they attribute their symptoms to a specific cause (e.g. sleep deprivation) which they can discuss, rather than talking about mood (Scrandis, 2005).

### 4.2.14 Nature and severity of the mental health difficulty

Mothers who are seriously unwell may benefit less from hearing other people's stories or having others react to their story **(C-Individual 13)** (Frank, 1998; Rennick-Egglestone et al., 2019b). In addition, while some peer support programmes are open to any mother experiencing mental health difficulties during the perinatal period, others only offer peer support to mothers whose difficulties are *directly connected* to motherhood and are not pre-existing or chronic. For example, Bluebell does not support mothers "whose symptoms are due to other factors such as relationship break down, physical or emotional abuse, poor housing or substance misuse and dependence ... people with long-term or severe mental health challenges, or who are involved with social services" (Bluebell, undated-a). As well as focusing peer support on mothers they consider most likely to benefit from it, these restrictions may help to create a more cohesive 'peer' experience for mothers (researcher's inference).

## 4.2.15 Self-esteem and internal locus of control

A person's psychological traits can affect their vulnerability to the negative effects of social comparisons **(C-Individual 14)**: people with lower global self-esteem and a lower internal locus of control have been found to be more likely to make negative social comparisons with peers (Bogart & Helgeson, 2000).

#### 4.2.16 Suitable pool of potential volunteers available

One-to-one programmes need to match suitable peers with mothers seeking support (McLeish et al., 2016a), and those offering group support need to ensure that their group leaders are equipped with the necessary facilitation skills (Rosenberg, 1984). For programmes whose peer supporters are volunteers, this requires careful recruitment and training. Volunteer models of peer support rely on the existence in the local community of a sufficient number of mothers with peer experience who have the motivation, time and other resources (e.g. childcare) that enable them to commit to a period of training and volunteering, are sufficiently well to be able to volunteer safely, and have the empathy and non-judgemental attitude which are essential for successful support **(C-Society 9)** (McLeish et al., 2016a).

## 4.3 Candidate mechanisms and outcomes

#### 4.3.1 **Evidence sources**

Evidence reviews, commentaries and theoretical papers were used to understand how the mechanisms of mental health peer support have been theorised to create psychological outcomes ('*what is it ... that works ... in what respects* and *why*?') (Davidson et al., 1999; Dennis, 2003b; Helgeson & Gottlieb, 2000; Mead et al., 2001; Morrell et al., 2016; Rappaport, 1994; Rennick-Egglestone et al., 2019a; Repper, 2013; Rosenberg, 1984; Salzer & Shear, 2002; Taylor, 2000; Thoits, 1986, 2011; Watson, 2017). In addition, this section drew on studies reporting the creation of theoretical change models based on qualitative findings (Gillard et al., 2015; Rennick-Egglestone et al., 2019b), or using theory to interpret quantitative findings (Bracke et al., 2008), or reporting evaluation of community-based programmes (Billsborough et al., 2017; Faulkner & Basset, 2012). Finally it drew on studies and reviews that explored the dynamics of one-to-one or group support more generally (Cohen et al., 2000; Darwin et al., 2017; Morrell et al., 2016; Rimé, 2009; Westhorp, 2008).

#### 4.3.2 Labelling of mechanisms and outcomes

In the narrative sections that follow, mechanisms are labelled (M) and outcomes are labelled (O). Mechanisms all concern the reasoning and reactions of the individual mother, leading to individual outcomes, so unlike contextual factors there is no additional labelling to indicate system levels.

#### 4.3.3 Mechanisms and outcomes in non-theoretical studies

Non-theoretical studies of community-based mental health peer support identified the proximate outcomes as hope, empowerment, finding a voice, confidence, self-esteem, reduced isolation, and receipt of information and advice; and highlighted the peer support mechanisms of empathy, understanding, non-judgemental acceptance, feeling able to speak openly, access to others' knowledge, and the opportunity to support others (Billsborough et al., 2017; Faulkner & Basset, 2012).

### 4.3.4 Understanding mechanisms and outcomes through middle range theory

The exploratory search identified a variety of middle range theories that have been suggested to explain the mechanisms through which peer support may affect outcomes. These theories are relevant both to asymmetrical support from trained peer supporters and horizontal support between people attending a support group.

Some of these middle range theories have a much wider application in social science, but they are discussed here only in relation to peer support. Social exchange theory directs attention to the costs
as well as the rewards of social interactions (Homans, 1961; Thibaut & Kelley, 1959), and Stewart and Tilden (1995) noted that social relationships may include conflict, criticism, emotional overinvolvement, and failed attempts at support. In this review, equal attention has been paid to the potential unintended negative mechanisms and outcomes of peer support.

#### 4.3.5 Social comparison theory

Social comparison theory suggests that a person's need for self-evaluation may in part be met by comparing their abilities, opinions and performance to those of similar others, and predicts that affiliative behaviour to enable social comparison is particularly likely in situations of anxiety or uncertainty (Festinger, 1954). Peers can therefore become "reference individuals against whom the distressed person can compare his or her situational appraisals, emotional reactions, and coping behaviors" (Thoits, 2011, p. 154).

## 4.3.5.1 *Positive implications*

A person's self-evaluation can be affected in different ways by lateral, upward and downward comparison. Lateral comparison (M) with a peer who is currently similar can normalise experiences and feelings that one has believed to be signs of unique failure, improving self-esteem (O) (Thoits, 2011). Upward comparison (M) with a peer who is further on the path to recovery may engender hope (O) for one's own recovery (Thoits, 2011). Downward comparison (M) with a peer who is less well can help to put one's own problems in perspective (O) (Wills, 1981), and could "maintain positive affect by providing examples of how bad things could be" (Salzer & Shear, 2002, p. 360). Affiliation in support groups is particularly likely for people affected by a condition that is stigmatised (Davison et al., 2000).

#### 4.3.5.2 *Negative implications*

Social comparison is not always psychologically beneficial. Helgeson and Gottlieb (2000) described how lateral comparison (M) may produce feelings of isolation and deviance (O) if peer group members do *not* validate experiences and feelings, for example because they are from different socio-economic or cultural backgrounds, have different responses to the situation, and have little else in common. Upward comparison (M) with peers who are less unwell may be frustrating and demoralising (O). Downward comparison (M) with peers who are more unwell may trigger anxiety about deterioration (O). Rennick-Egglestone et al. (2019b) found that being exposed to the narratives of others who have made a better recovery can generate feelings of inadequacy or disconnection (O), while the experiences of people whose problems are less serious can seem irrelevant (O).

#### 4.3.6 **Overcoming stigma and shame**

Sociologists Cooley (1902) and Mead (1934) described the importance of the 'looking glass self' in the development of self-concept - how we think others see us affects how we see ourselves. Although there is a complex relationship between self-esteem and membership of a group that is socially devalued, those who internalise negative views ('self-stigmatisation') are at particular risk of low self-esteem (Crocker & Major, 1989). In his influential account of stigmatised identities, (Goffman) described how "self-hate and self-derogation can also occur when only he and a mirror are about" (1963, p.7).

#### 4.3.6.1 *Positive implications*

Goffman proposed that affiliation with similar others can provide a positive alternative in-group identity (O) by creating a different reference group for reflected appraisal (M), as well as offering a place where the stigmatised person no longer has to undertake the labour of concealment (M). Brown (2006) likewise identified the formation of mutually empathetic relationships, especially with others who have had similar experiences, as a crucial element of resilience to shame. In particular she described how normalisation by others (M) of the experience that has led to shame could overcome its isolating effect (O).

#### 4.3.6.2 Negative implications

Goffman suggested that learning to identify with a socially devalued group (M) can initially reduce one's own sense of value (O), and a person may try to retain belief in their own 'normality' by distancing their self-perception from their perception of others sharing the same stigma: "What may end up as a freemasonry may begin with a shudder" (1963, p.37).

#### 4.3.7 **Peer support groups as normative narrative communities**

Kleinman (1988), from the perspective of medical anthropology, and Frank (1998), from the perspective of medical sociology, described the significance of illness narratives in patterning and communicating the subjective experience of illness. Rappaport (1994) applied a narrative studies framework to self-help groups and viewed them as communities which offer a narrative about themselves.

#### 4.3.7.1 *Positive implications*

Rappaport argued that people who join self-help groups are not necessarily seeking 'treatment' but rather seeking answers to identity questions, such as 'Who am I?', and 'Who can I hope to become?', and that exposure to the caring, mutual ethos of self-help groups (M) can foster new personal narratives of hope and capacity for positive change (O). Davidson et al. (1999, p. 168) likewise suggested that peer support "may offer worldviews and ideologies to assist persons in making sense

of their experiences". For Mead et al. (2001), writing from a civil rights perspective about people who had been disempowered in the mental health system, the peer support group could challenge the medical model of mental health: "we can practice seeking and finding new ways of making meaning and see ourselves from vantage points of personal worth and social power" (p.8-9).

In the context of postnatal depression, Thoits (1985) argued that where a new mother feels a discrepancy between her true feelings and society's normative emotional response to motherhood, she may label herself as mentally ill. Peer support can overcome her sense of social deviance (O) by re-labelling these feelings as normative (M) and confirming they have "understandable origins in objective conditions" (p.235). Taylor (2000) also identified postnatal self-help groups as offering participants a new collective identity - peer support "encourages women to trade their guilt, shame and depression for anger and pride over the injustices of motherhood and having 'survived' a condition" (p.290). At the same time, Taylor considered the paradox that that self-help groups implicitly reaffirm the cultural trope of maternal contentment by holding out the hope that mothers will eventually 'recover' and be restored to 'normality'.

#### 4.3.7.2 Negative implications

The 'normative narrative community' of a peer support group may undermine authenticity (O) by creating pressure to conform to the group's construction of meaning (M). Frank (1998) described three categories of illness stories: restitution, chaos, and quest. Frank noted that listeners may have difficulty coping with chaos stories, when they want to hear a reassuring restitution narrative that ends with the restoration of health, or a satisfying quest story that incorporates the discovery of new meaning, insights, or personal qualities. Morgan et al. (2015) critiqued the trend in mental health recovery narratives to focus on a positive linear path to wellness, which can marginalise people whose situation does not have an upward trajectory. Rennick-Egglestone et al. (2019b) also found that the helpfulness of sharing or receiving a recovery narrative could be reduced during a period of mental health crisis.

# 4.3.8 Social learning

Bandura's social learning theory (1977) described how learning can occur through observing the behaviour of others and its consequences. He argued that social learning can influence a person's self-efficacy beliefs, which affect their motivation to try and persist with new behaviours. The social learning effect is strengthened when the role model has peer experiences and in particular where they have succeeded in overcoming difficulties (Bandura, 1986).

#### 4.3.8.1 *Positive implications*

This means that peers can role model effective coping behaviours and enhance self-efficacy beliefs about taking steps towards recovery (O), by giving positive feedback about performance so far, providing vicarious experience of success, normalising emotional reactions, and sharing coping strategies (M) (Bandura, 1977, 1986; Dennis, 2003b; Salzer & Shear, 2002; Thoits, 2011).

Although social learning theory might appear to be particularly relevant for interventions based around peer *education* rather than peer *support* (Turner & Shepherd, 1999), Davidson argued that peer support also creates a behavioural setting conducive to learning information and skills, and being open to new ideas: "coping strategies or alternative perspectives, and being exposed to successful role models, allowing for vicarious learning, modelling, and an enhancement of problemsolving skills" (1999, p. 168).

#### 4.3.8.2 *Negative implications*

Alternatively, there is a risk in a peer support group that the normalisation of negative emotions may create a downward spiral where, through constant reciprocal disclosure and a focus on negative feelings (M), group members come to perceive themselves as even more distressed than they thought they were (O) (Helgeson & Gottlieb, 2000).

#### 4.3.9 Experiential knowledge and expertise

Experiential knowledge is "truth learned from personal experience with a phenomenon" (Borkman, 1976, p. 446), distinct from professional knowledge acquired by training and professional practice. It has two components – information gained from experience, and the belief that information derived from personal experience is a legitimate source of truth. A related concept is 'experiential expertise' - the "competence or skill in handling or resolving a problem through the use of one's own experience" (Borkman, 1976, p. 447).

#### 4.3.9.1 *Positive implications*

For Borkman, the essential equality in a self-help group is derived from the recognition that everyone participating is a peer by virtue of experiential knowledge. This means that people feel they have the right to speak, that they will be understood, and that they can trust the experiencebased information shared by peers (M). Those who have more experiential expertise serve as role models and sources of hope (O) for newcomers in a group, and may be valued sources of advice (O).

In considering how experiential knowledge, which is by definition specific to the individual, can be of value to others, Borkman hypothesised that this is a function of the group setting: "by pooling the experiences of a number of people, the common elements of the problem and attempts to cope with it emerge, while simultaneously highlighting the uniqueness of each individual's situation... the

group is protected against inapplicable knowledge that is too idiosyncratic or peculiar" (Borkman, 1976, p. 450). This raises the question of its safe applicability in one-to-one peer support relationships.

#### 4.3.9.2 Negative implications

Peer support group members may share ineffective or harmful ways of coping, or inaccurate information. Other group members may trust this experiential knowledge (M) in preference to the (implicitly evidence-based) expertise of professionals, leading to adoption of ineffective or harmful behaviours (O) (Helgeson & Gottlieb, 2000).

#### 4.3.10 Social support theory

#### 4.3.10.1 Multi-dimensional model of social support

Peer support has been analysed as a form of social support (Dennis, 2003b; Salzer & Shear, 2002; Thoits, 2011), a multi-dimensional concept defined by House (1981, p. 26) as "a flow of emotional concern, instrumental aid, information, and/or appraisal (information relevant to self-evaluation) between people". Emotional support means feeling accepted, encouraged, and cared for through sympathetic listening to ventilation of feelings (M), leading to increased positive affect (O) (Cobb, 1976; Cohen & Wills, 1985). Emotional support enhances self-esteem (O), particularly where this is threatened, "by communicating to persons that they are valued for their own worth and experiences and are accepted despite any difficulties or personal faults" (Cohen & Wills, 1985, p. 313). Instrumental support means help (M) to resolve practical problems (O)(Cobb, 1976; Cohen & Wills, 1985). Informational support gives the recipient access to advice and guidance (M) relevant to problem-solving (O) (Cutrona & Russell, 1990). Appraisal support includes feeling affirmed and encouraged by positive feedback about emotions, cognitions and behaviour (M), leading to the bolstering of self-esteem or a sense of competence (O) (Cutrona & Russell, 1990; Wills, 1985). Many theorists add *companionship and belonging support* - meaningful social contact with others, which leads to increased positive affect (O) through feeling accepted and included (M) (Baumeister & Leary, 1995; Cohen & Wills, 1985; Cutrona & Russell, 1990).

#### 4.3.10.2 *Direct effect and stress-buffering models*

Theorists have proposed a distinction between the direct and buffering effects of social support. In the *direct (main) effect* model, social support is understood to have a direct impact on positive affect (O) even in the absence of stressors, for example by reducing feelings of isolation, and increasing a sense of belonging and acceptance (M) (Cohen et al., 2000; Cohen & Wills, 1985; Dennis, 2003b; Thoits, 2011).These are seen as core human needs for emotional wellbeing (Baumeister & Leary, 1995; Maslow, 1943). In the *buffering effect* model, social support is understood to operate specifically during times of stress to moderate the potential impact of stressors (Cohen et al., 2000; Cohen & Wills, 1985). This drew on Lazarus and Folkman (1984)'s theory of stress and coping, which conceptualised psychosocial stress as the combination of an objective stressor, a person's subjective cognitive appraisal of the stressor, and their reaction in the light of this appraisal. Coping is therefore understood as a process of "ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus, 1993, p. 237). Observational studies consistently find that women are more likely than men to respond to stress by turning to social support (Tamres et al., 2002). Taylor et al. (2000) suggested that the strength of the mammalian biobehavioural 'flight-or-flight' stress response may be gendered, as those behaviours are not necessarily adaptive for a female who is pregnant or has immature offspring. They theorise that females are more likely to find protection for themselves and their offspring within the social group, and therefore have a 'tend-and-befriend' stress response.

Social support may provide three forms of coping assistance: (1) problem-focused coping (M), which helps to resolve the issue (O); (2) perception-focused coping, which affects appraisal of the stressor and helps to cognitively redefine it as less threatening (O), for example by reframing its meaning or increasing the person's belief in their ability to cope (M); and (3) emotion-focused coping, which alters the person's reactive self-perception (M) so that their self-esteem may increase (O), or reduces negative emotional reactions (O) through sharing coping strategies (M) (Cohen et al., 2000; Cohen & Wills, 1985; Dennis, 2003b; Pearlin & Schooler, 1978). These forms of coping assistance are similar to the functional dimensions of social support (Cutrona & Russell, 1990). Informational and instrumental support can assist problem-focused coping; appraisal support can assist perception-focused coping; appraisal support can assist perception-focused coping.

#### 4.3.10.3 *Positive implications*

Dennis (2003b) and Thoits (2011) proposed a distinction between how the functional dimensions of social support may operate, according to whether the support is given by significant others or by people with peer experiences. They both argued that peers can uniquely offer empathetic understanding, acceptance of negative emotions, and validation of feelings (M), leading to increased positive affect (O). Information, problem-solving advice, encouragement, affirmation, and threat reappraisal from peers may be experienced as particularly realistic and credible (M), leading to more effective problem resolution and a stronger impact on negative affect (O). By contrast, well-meaning attempts by significant others to provide these may be counter-productive: "Because of experiential dissimilarity, the information or advice they offer will seem too generic, inappropriate, or even misguided to the distressed individual, and their encouraging faith in his or her ability to handle the problem may seem naïve or unrealistic. A sense of alienation or social isolation may follow"(Thoits,

2011, p. 153). Alternatively, family and friends may try to deal with their own distress about the situation by minimising the person's problems or refusing to hear them talked about; or they may be one of the sources of stress (Helgeson & Gottlieb, 2000; Thoits, 2011). These differences have been confirmed by empirical studies of peer support (e.g. Billsborough et al., 2017).

## 4.3.10.4 Negative implications

Social support theorists have noted that the choice of the functional aspect of support offered (emotional, appraisal, informational or instrumental) is key to its success. Where the aspect of support *received* does not match the aspect of support *desired* by the person receiving the support (M), it may be ineffective or may increase rather than diminish stress (O) (Cohen & Wills, 1985; Sarason et al., 1990; Thoits, 1986).

## 4.3.11 Helper-therapy principle

The helper-therapy principle (Riessman, 1965) describes the positive effects of support on the person who gives it, irrespective of benefits to the person receiving the support.

#### 4.3.11.1 Positive implications

Within a peer support group there is the opportunity to give peer support to others (M) as well as to receive it, which can lead to a sense of interpersonal competence and social approval (O). This can also give a person a positive self-image derived from helping someone else; a strengthened sense of their own wellness; and a more positive role identity (O) "in which they no longer are restricted to a passive role of 'patient' relying on expert advice but now also may serve as role models for newer members, [and] provide feedback and assistance to others" (Davidson et al., 1999, p. 168).

## 4.3.11.2 Negative implications

Listening to other people's problems at a group may be distressing, and supporting others at the group may be burdensome instead of empowering (O) (Helgeson & Gottlieb, 2000). It can be particularly depressing (O) to learn of other people's distress and lack of successful recovery (Rennick-Egglestone et al., 2019b).

#### 4.3.12 Attachment theory

Attachment theory (Ainsworth et al., 1978; Bowlby, 1969/1982) links the development of early relationships with primary caregivers to an internal working model of the self and others, which affects the adult's confidence in forming relationships, expectations about relationships, and emotional expressiveness and trust within relationships. Attachment is a resource that is activated by children when in distress (Bowlby, 1969/1982) and adults in emotional distress will likewise be motivated to seek out emotional support from attachment figures (Rimé, 2009).

#### 4.3.12.1 Positive implications

This has provided the theoretical basis for many one-to-one social support interventions which are predicated on the development of a relationship of trust (Eckenrode & Hamilton, 2000). Sarason et al. (1990) described perceived social support as providing a sense of acceptance (M) which can be understood as "the adult equivalent of attachment" (p.106) (O). By contrast Gillard et al. (2015) argued that while peer support workers do not improve attachment for adults with an insecure attachment style, they can build relational bonds which promote attachment to the mental health service team (O). In the context of support groups, Rosenberg (1984) saw the role of the group leader as "helping the group become the prototype of the well-regulated integrated family... in the healthy family individuals feel loved and protected and able to reveal the negative aspects of self they would hide from the world" (p.179) (M).

#### 4.3.12.2 Negative implications

In the context of one-to-one support interventions, Westhorp (2008) drew on attachment theory to argue that some parents' insecure, ambivalent and disorganised attachment styles may affect both their ability to engage with one-to-one support, and the meanings they draw from it (for example, judging themselves negatively for needing support) (M). Eckenrode and Hamilton (2000) and Darwin et al. (2017) drew attention to the sense of loss and grief (O) that can be experienced when the one-to-one support is withdrawn, if the close and confiding relationship has felt like friendship and formed the 'secure base' for an experience of positive attachment (potentially for the first time) (M). People who participate in time-limited support groups often express the wish that the group would not end (Cohen et al., 2000).

#### 4.3.13 Self-disclosure

Expressing emotion openly may be cathartic (Scheff & Bushnell, 1984), and Jourard (1971) argued that full self-disclosure to at least one other person is essential for a healthy personality. Altman and Taylor (1973) linked the development of relationships to the progressive depth of reciprocated self-disclosure, so someone who feels inhibited from disclosing mental health difficulties to their partner, family and friends may feel emotional estrangement in these relationships. Humanistic therapy is based on person-centred principles, which are believed to make it possible for the person receiving support to express themself with authenticity and develop a more positive self-concept (O) (Rogers, 1956). Bordin (1979) described the key features of any therapeutic alliance as understanding, validation, and respect (M). In humanistic therapy, Rogers (1956) defined the core conditions as genuineness, which can include self-disclosure by the therapist; full acceptance (unconditional positive regard); and empathy (M).

## 4.3.13.1 Positive implications

As empirical studies of mental health peer support have consistently found its key features to include non-judgemental acceptance, empathy and bringing oneself to the relationship (Billsborough et al., 2017; Bradstreet, 2006; Davidson et al., 1999; Faulkner & Kalathil, 2012; Gillard et al., 2017; Repper & Carter, 2011), it has been argued that these core conditions also underpin non-therapeutic relationships with trained peer supporters (M), and enable people to speak to peer supporters honestly (O) (Gillard et al., 2015; Watson, 2017).

#### 4.3.13.2 *Negative implications*

The notion that venting emotions is intrinsically cathartic has been challenged. Rimé (2009) argued that where negative emotions are shared socially, a socio-affective response (i.e. emotional support to enable emotion focused-coping) brings only short term relief, whereas a socio-cognitive response (i.e. appraisal support to enable perception-focused coping) is necessary to enable emotional recovery. If the emphasis is only on listening to and empathising with the person's distress (M), this may actually intensify the original emotions and lead to increased rumination and intrusive thoughts (O).

#### 4.3.14 Self-compassion theory

Neff (2003) proposed self-compassion as an alternative construct to self-esteem, based on selfacceptance as an imperfect person rather than on self-evaluation. This involves self-kindness; mindful awareness of painful thoughts or feelings rather than over-identification with them; and recognition that to struggle is part of shared human experience, not the unique failing of the individual. Neff described this as closely related to the self-aware, unconditional self-acceptance that humanistic psychologists aimed for their clients to achieve, but she positioned self-compassion on the less individualistic ground of common humanity rather than self-actualisation. Self-compassion could also be seen as a positive form of emotion-focused coping (Cohen & Wills, 1985).

# 4.3.14.1 Positive implications

Peer support can encourage self-compassion explicitly (O), through reframing negative experiences and emotions as a shared motherhood experience deserving of compassion rather than criticism (M), and suggesting that mothers do not need to try to reach impossible standards (M). It can also work implicitly, by offering non-judgmental acceptance of current thoughts and feelings (M) and offering opportunities to be compassionate towards others, both of which can lead to greater selfacceptance (O) (researcher's inference).

#### 4.3.15 **Overlap with principles of group psychotherapy**

Many of these theories describe social psychological mechanisms that have also been identified as the active ingredients of group psychotherapy, irrespective of the psychotherapeutic approach. For example, Yalom and Leszcz (2005) identified common 'therapeutic factors': instillation of hope (upward social comparison); universality (lateral social comparison, overcoming stigma); imparting of information (experiential knowledge, informational support); altruism (helper-therapy); corrective recapitulation of the primary family group (attachment theory); imitative behaviour (social learning); group cohesiveness (social support – belonging); catharsis (self-disclosure); and existential factors (normative narrative communities).

Rosenberg (1984) argued that this overlap in curative factors makes support groups intrinsically therapeutic but that "the therapeutic aspect is tangential because the emphasis is on comfort rather than cure" (p.178). She identified the main basis of support groups as the development of cohesive identity and the enhancement of self-esteem, leading to improved coping, whereas group therapy emphasises problem-solving, self-awareness and personality change.

#### 4.3.16 **Overlap with other forms of volunteer support**

Additional dynamics are created when the peer supporter is a volunteer. Receiving support from an unpaid volunteer has an intrinsic psychological benefit for some mothers with low self-esteem who experience the gift of another person's time as an affirmation of their own worth (McLeish & Redshaw, 2015).

Whether the volunteer will be offering one-to-one support or leading a group, the role can be a subtle and complex one. Volunteers need to be able to recognise and respond flexibly to the varied dynamics that women may want from peer support: "some want equal and mutual while others want to be 'held'" (MIND & McPin Foundation, 2019, p. 14). Just as for employed peer workers (Wood, 2020), in order to safely offer peer support from volunteers, programmes need a robust recruitment process; realistic training; an effective matching process for one-to-one support; and supervision and emotional support during their period of volunteering (McLeish et al., 2016a). Dennis (2003b) cautioned that, while training is essential, too much training may lead to professionalisation and a loss of 'peerness'; but she acknowledged that the amount of training that might turn peers into paraprofessionals was unknown.

#### 4.3.17 Minimising ineffectiveness and overcoming negative effects

Helgeson and Gottlieb (2000) considered why peer support groups may be ineffective. For example, the duration of the group may be too short (e.g. 6-8 weeks) for members to become comfortable talking openly (M). Expressing feelings and experiences may not on its own be enough to reduce

psychological distress, as the person's underlying thoughts, feelings, self-awareness and coping mechanisms may remain unchanged (M); the person may feel disappointed if they expected an improvement in their symptoms (O). The balance between emotional support and information exchange may not be appropriate for an individual's current coping needs (M).

Helgeson and Gottlieb (2000) suggested that the effectiveness of support groups can be maximised by careful selection of members, for example trying to achieve reasonable homogeneity, and screening out people who are highly distressed. They also described how some of the potential harmful effects of peer support can be mitigated through active skilled facilitation by a group leader. The facilitator can help members to make meaning from their experiences; suggest ways of coping; offer an alternative to inaccurate or unhelpful advice from group members; encourage members to move beyond dwelling on negative feelings and end the session on a positive note; and counter negative social comparisons and model positive social comparisons for members with low selfesteem, who are more likely to make negative social comparisons (Bogart & Helgeson, 2000). It may be argued that a peer support group facilitated on these lines by a non-peer may be difficult to distinguish from a therapy group.

## 4.4 Chapter summary

This chapter has described the candidate contexts, mechanisms and outcomes identified through exploratory searching and retroductive theorising, which were used to develop the initial theoretical model for take-up and use of perinatal mental health peer support. There are a wide range of potential contextual factors, at micro-, meso- and macro-level, that may affect mothers' decision to use peer support and the mechanisms by which peer support works. There are also a range of potential mechanisms through which peer support may produce both positive outcomes and unintended negative consequences.

The next chapter presents part 2 of the results of the realist review, including the search for empirical studies of perinatal mental health peer support, C-M-O analysis, and the testing of the initial theoretical model against the C-M-O analysis to create the final theoretical model which shows the full C-M-O configurations.

# 5 Realist Review - Results, Part 2

#### Chapter overview

This chapter is part 2 of the findings of the realist review. It presents the results of the search for empirical studies directly related to perinatal mental health peer support interventions, which resulted in the inclusion of 29 sources covering 22 interventions. It then presents the final theoretical model, which combines the initial theoretical model (based on the contexts, mechanisms and outcomes identified in Chapter 4) and the testing of the C-M-O analysis of empirical studies against that model. It concludes with a discussion of the differences between the initial and final theoretical models, and the strengths and limitations of the realist review.

## 5.1 The empirical studies

This section presents the results of the search for empirical studies to test the initial theoretical model. The inclusion and exclusion criteria and the basis for quality assessment have been described in Chapter 3. The Prisma flow diagram of the results of the searches is shown in Figure 4.

The search for empirical studies identified 29 sources - peer-reviewed articles (n=23), doctoral theses (n=3), and reports from community groups (n=3). These described a total of 22 perinatal mental health peer support programmes or randomised controlled trials that met the inclusion criteria. In this chapter, these programmes and trials are collectively referred to as 'interventions' and are referred to by the number shown in Table 4, which also gives details of each intervention and its reporting. Five interventions were described in more than one source; where there were multiple sources reporting the same intervention, these have been grouped under a single intervention number. Some of the interventions were closely-related models with the same researchers involved: these have been identified in Table 4 through the use of a dotted line to separate related interventions.

Although one of the trials (#6) was described by the authors as intended to assess the impact of peer support on the *prevention* of postnatal depression (Dennis et al., 2009), this review follows the approach of the National Institute for Health and Care Excellence (2014) in classifying this as a peer support intervention for mothers *with symptoms of postnatal depression*, since the intervention was only offered to postnatal mothers who scored >9 on the Edinburgh Postnatal Depression Scale.



## Figure 4 PRISMA flow diagram for the search for empirical studies

# Table 4 Empirical studies included: characteristics of the interventions and the studies

A dotted line separates interventions that were closely connected with the same researchers involved. Articles that relate to the same intervention are grouped within thick solid lines and given a single intervention number.

Intervention #	Author (date), location	Methodology	Number of qualitative informants	Number of participants in quantitative study	Type of peer support and setting	Frequency	Perinatal mental health criteria	Referral of mothers	Reported characteristics of mothers	Baby's age	Inclusion of mothers with mental health history	Training for volunt- eers	Characteristics of volunteers	Co- creation by peers	Use in review
1	Anderson (2013), USA	Qualitative: interviews (phenomen- ology)	7 mothers	N/A	Group (leader unclear) No details of setting	No details	Postnatal depression (self- defined)	By doctor or self- referral	Aged 18+	No details	No details	N/A	N/A	No details	Limited
2	Cust (2016), UK	Pilot RCT: psychological scores, interviews and log books	11 mothers 7 volunteers	30 (15 received peer support)	1:1 face- to-face At home or place of mother's choice	6 weekly sessions x 1 hour	Postnatal depression (EPDS 11- 16)	Health visitor	Aged 25-35. All White British. All first time mothers. All had post- secondary education.	6 weeks	Excluded	1 day	Recovered from mild to moderate depression.	Yes	Medium
	Carter et al. (2018), UK	Qualitative: interviews and log books	7 volunteers												High
3	Carter et al. (2019), UK	Qualitative (within feasibility study): interviews and log books	9 mothers 4 volunteers	20 (10 received peer support)	1:1 face- to-face. At home or place of mother's	6 weekly sessions x 1 hour	Antenatal depression (Whooley screening questions)	Community midwife	All spoke English. All first time mothers.	Pregn- ancy (28-30 weeks)	Excluded	2 days	Recovered from antenatal depression.	Yes	Medium
	Cust and Carter (2018), UK	Researcher's reflections on process	N/A		choice										High

Intervention #	Author (date), location	Methodology	Number of qualitative informants	Number of participants in quantitative study	Type of peer support and setting	Frequency	Perinatal mental health criteria	Referral of mothers	Reported characteristics of mothers	Baby's age	Inclusion of mothers with mental health history	Training for volunt- eers	Characteristics of volunteers	Co- creation by peers	Use in review
4	Chen et al. (2000), Taiwan	RCT: psychological scores	N/A	60 (30 received peer support)	Group (led by nurse). No details of setting.	4 weekly sessions x 1.5-2 hours	Postnatal distress (Taiwanese BDI 10+)	On postnatal wards	Aged 18+ 50% had at least senior high school education. Two-thirds first time mothers. Range of social class.	6-10 weeks	No details	N/A	N/A	No	Limited
5	Dennis (2003a), Canada	Pilot RCT: psychological scores, questionnaires	20 mothers & 16 volunteers	42 (20 received peer support)	1:1 by telephone	No fixed amount, during 2+ months.	Postnatal depression EPDS >9	Public health nurses	Aged 18+. All spoke English. Most born in Canada. Most had a partner. Most had post- secondary education.	8-12 weeks	Excluded (if recent or chronic)	4 hours	Recovered from postnatal depression. Most were married. Most had post- secondary education.	No	Medium
6	Dennis et al. (2009), Canada Dennis (2010), Canada Dennis (2013), Canada	RCT: psychological scores, questionnaire Questionnaire Questionnaire	221 mothers 221 mothers 121 volunteers	701 (349 received peer support)	1:1 by telephone	No fixed amount, during 12+ weeks.	Postnatal depression EPDS >9	Public health nurses	Aged 18+. All able to speak English. 93% married. 80% had post- secondary education. 21% non- Canadian.	2 weeks	Excluded if currently taking medicat- ion	4 hours	Recovered from postnatal depression. 82% married. 92% had post- secondary education. 39% first time mothers. 54% non- Canadian.	No	High High Medium
	Dennis (2014a), Canada	Description of process	N/A												Limited

Intervention #	Author (date), location	Methodology	Number of qualitative informants	Number of participants in quantitative study	Type of peer support and setting	Frequency	Perinatal mental health criteria	Referral of mothers	Reported characteristics of mothers	Baby's age	Inclusion of mothers with mental health history	Training for volunt- eers	Characteristics of volunteers	Co- creation by peers	Use in review
7	Duskin (2005), USA	Qualitative: interviews	5 mothers	N/A	Group (led by graduate students). At medical centre.	No details	Postnatal depression & anxiety (self- report)	No details	Aged 37-42. 4 White, 1 Latina. All first time mothers. All married. All high socio- economic status.	2 weeks - 4 months	Included	N/A	N/A	Unclear	High
8	Eastwood et al (1995), UK	Quasi- experimental pre-test/post- test: psychological scores, questionnaire; researchers' observations	8 mothers	N/A	Group (led by health visitors). At commun- ity clinic.	12 weekly sessions.	Postnatal depression and anxiety	No details	Aged 19-35. Social class II-V Mostly not first time mothers. Most had a partner.	No details	Included	N/A	N/A	No	Limited
9	Field et al. (2013a), USA	Parallel group RCT peer support vs IPT: psychological scores, cortisol levels	N/A	44 (22 received peer support)	Group (no leader). No details of setting.	12 weekly sessions x 20 minutes.	Antenatal depression (clinical interview)	At ultrasound clinic	Aged 20-38. Mostly Hispanic or African- American. Mostly low income, high- school education. >1/3 had no partner.	Pregn- ancy	Excluded	N/A	N/A	No	Medium
10	Field et al. (2013b), USA	Parallel group RCT peer support vs yoga: psychological scores, cortisol levels	N/A	96 44 received peer support)	Group (no leader). No details of setting.	12 weekly sessions x 20 minutes.	Antenatal depression (clinical interview)	At ultrasound clinic	Aged 18-40. Mostly Hispanic or African- American. Mostly low income, high- school education. >1/3 had no partner.	Pregn- ancy	Excluded	N/A	N/A	No	Medium

Intervention #	Author (date), location	Methodology	Number of qualitative informants	Number of participants in quantitative study	Type of peer support and setting	Frequency	Perinatal mental health criteria	Referral of mothers	Reported characteristics of mothers	Baby's age	Inclusion of mothers with mental health history	Training for volunt- eers	Characteristics of volunteers	Co- creation by peers	Use in review
11	Gjerdingen et al. (2013) USA	Pilot RCT peer support vs doula or control: psychological scores	N/A	39 (13 received peer support)	1:1 by telephone	No fixed amount.	Postnatal depression PHQ-9 (cut off not stated)	Hospitals, local practices, websites, Early Childhood & Family Education	Mean age 29.7. 95% White. 84% married. 44% first time mothers. 74% had post- secondary education. Mostly middle or high income.	From birth	No details	0.5 day	Recovered from postnatal depression.	No	Limited
12	Letourneau et al. (2015) Canada Letourneau	Quasi- experimental pre-test/post- test: psychological scores, questionnaire Description of	34 mothers	64 N/A	1:1 by telephone	Weekly for 4-12 weeks	Postnatal depression (EPDS 12- 19)	Telehealth nurses, public health nurses	Aged 17–43. 74% spoke English, 26% spoke French. 71% had post- secondary education. 41% babies had	Up to 24 months	Included	1 day	Recovered from postnatal depression. Aged 23-40. Spoke English or French.	Yes	Limited
	et al. (2016) Canada	process: qualitative interviews	stakeholders						spent time in neonatal intensive care.						
13	Ludwick (2017) USA	Description of process, researcher's field notes	N/A	N/A	Telephone group (led by graduate student).	Weekly	Postnatal depression (self- defined)	Self- referral	No details	3 weeks to 14 months	No details	N/A	N/A	Unclear	Limited
14	Maley (2002) USA	Description of process	N/A	N/A	Group (led by nurse/ social worker). No details of setting.	Monthly	Postnatal depression (self- defined)	Self- referral, doctors, community organisatio ns	Most had a supportive partner or family.	No details	No details	N/A	N/A	Yes	Limited

Intervention #	Author (date), location	Methodology	Number of qualitative informants	Number of participants in quantitative study	Type of peer support and setting	Frequency	Perinatal mental health criteria	Referral of mothers	Reported characteristics of mothers	Baby's age	Inclusion of mothers with mental health history	Training for volunt- eers	Characteristics of volunteers	Co- creation by peers	Use in review
15	Montgomery et al. (2012) Canada	Qualitative: observation and interviews (ethnography)	7 mothers observed in group & 3 interviewed	N/A	Group (led by peer). Commun- ity location accessible by public transport.	5 weekly sessions x 2 hours	Postnatal depression (self- defined)	Self- referral	Aged 18-30. All spoke English. All had at least high school education. All had a partner.	No details	No details	N/A	N/A	Yes	Limited
16	Pitts (1999) UK	Retrospective psychological scores & questionnaires	34 mothers, 32 health professionals	N/A	Group (led by health visitors). No details of setting.	Weekly	Postnatal depression (EPDS 12+, but admitted 2 women with 9)	Health visitors, GPs	No details	No details	No details	N/A	N/A	No	Medium
17	Prevatt et al. (2018) USA	Quasi- experimental pre-test/post- test: psychological scores, questionnaire with open text	25 mothers	45	Group (led by peers, with medical advisor). Waiting room of medical practice.	Weekly x 90 minutes.	Postnatal depression (self- defined)	Self- referral	Aged 22 to 45. 86% White. 85% married. 89% had post- secondary education. 58% first time mother.	No details	Included	No details	Recovered from postnatal depression.	Yes	Medium
18	Sembi (2018) UK	Pilot RCT & RCT: psychological scores, questionnaires, activity logs, interviews	PILOT: 6 mothers RCT: 12 mothers & 6 volunteers	RCT 28 (14 received peer support)	1:1 by telephone	No fixed amount, lasted 4 months	Postnatal depression (PILOT: EPDS 10-21 or Whooley questions; MAIN: EPDS 10- 22)	Health visitor, GP, self- referral	Aged 16+. All spoke English. 86% White British. 14% did not state ethnicity.	Up to 24 months	Included	8 hours (4 x 2 hour sessions)	Recovered from postnatal depression. All White British.	No	High

Intervention #	Author (date), location	Methodology	Number of qualitative informants	Number of participants in quantitative study	Type of peer support and setting	Frequency	Perinatal mental health criteria	Referral of mothers	Reported characteristics of mothers	Baby's age	Inclusion of mothers with mental health history	Training for volunt- eers	Characteristics of volunteers	Co- creation by peers	Use in review
19	Shorey et al. (2019) Singapore	RCT: psychological scores, questionnaires	N/A 10 mothers &	138 (69 received peer support) N/A	1:1 by telephone / text/ WhatsApp	No fixed amount, lasted 4+ weeks	Postnatal depression (EPDS >8)	Nurses on postnatal ward	Aged 23-43. 43% Chinese. 34% Malay. Mostly first time mothers. 96% married. 60% had post- secondary education. Aged 25 -40.	From birth	Excluded	0.5 day	Recovered from postnatal depression. Aged 21+. All spoke English. 42% Chinese 34% Malay	No	Limited
	Shorey and Ng (2019) Singapore	Qualitative interviews	10 mothers & 19 volunteers	N/A					Aged 25 -40. 50% Chinese. 45% Malay.				Recovered from postnatal depression. Age 25-54 90% Chinese		Medium
20	Acacia Family Support (2019) UK	Psychological scores, questionnaires	N/A	159 mothers	1:1 face- to-face. Communi- ty centre.	No fixed amount, No time limit.	Antenatal/ postnatal depression or anxiety (self- defined)	Self- referral, midwives, health visitors, GPs, other agencies	No details for peer support specifically. For all services: 1/3 from Black, Asian or Minority Ethnic communities. 50% living in deprived areas.	Preg- nancy and up to 2 years	No details	1 day core	Majority had experience of postnatal depression or other mental health issues.	Yes	Limited
21	Bluebell Care (Fairbairn & Kitchener 2020) UK	Psychological scores, questionnaires	N/A	126 mothers	1:1 face- to-face. At home or place of mother's choice.	6 sessions.	Antenatal/ postnatal depression or anxiety (EPDS and GAD7)	Self- referral or any health profession- al	No details.	Pregn- ancy and up to 2 years	No details	unclear	First-hand experience of perinatal mental health difficulties.	Yes	Limited
22	Happy Mums (Lynch 2019) UK	Qualitative interviews/ focus groups; survey	21 mothers; 16 staff & volunteers; 28 stakeholders	N/A	Group (led by peer staff). Communi- ty centre.	Weekly - no time limit.	Any (self- defined)	Self- referral or profession- al	All White British	Pregn- ancy and up to 2 years	No details	unclear	Experience of perinatal mental health difficulties (own or supporting family/friend).	Yes	Limited

#### 5.1.1 Summary of interventions

The studies used a range of methodologies. Five interventions were reported through qualitative research only (#1,3,7,15,22), five through quantitative methods only (#4,5,9-11), ten through mixed methods (#2,6,8,12,16-21) and two were only reported through descriptions of the process of setting up and running the intervention (#13,14). Three interventions offered one-to-one support in person from trained volunteers (#2,3,20), one offered in-person support from a paid peer supporter (#21), and 11 offered in-person group support (#1,4,7-10,14-17,22). Six offered one-to-one telephone support from a trained peer volunteer (#5,6,11,12,18,19), with interventions #6, 12 and 18 being based on the approach piloted in #5. There was an attempt to deliver group telephone support in one intervention (#13) and this was also inspired by #5.

Eight interventions took place in the USA (#1,7,9-11,13-15), eight in the UK (#2,3, 6,16,18,20-22), four in Canada (#5,6, 12,15), one in Taiwan (#4) and one in Singapore (#19). Most were for mothers with postnatal depression, which was either self-defined by the mother (#1,7,13-15), or assessed using a validated self-report instrument (#2,4-6,8,11,12,16,18); only three had an upper threshold for scores (#2,12,18). Three interventions were for antenatal depression and identified eligible mothers using the Whooley screening questions (#3) or a structured clinical interview (#9,10). Two interventions were open to mothers with antenatal or postnatal depression or anxiety, self-defined (#20) or assessed using a validated self-report instrument (#21) and one was for any self-defined perinatal mental health difficulty (#22). Six interventions excluded mothers with a previous mental health history (#2, 3,5,9,10,19), five included these mothers (#7,8,12,16,18), eleven did not specify this (#1,4,6,8,11,13-15,20-22).

The length of interventions with a planned number of sessions ranged from four weeks to four months, but some gave no details about length or intensity (#1,7,11,) and some allowed the one-to-one peer support to continue past the expected length if the volunteer and mother chose this (#5,6,19). The frequency was weekly in almost all interventions that had a fixed number of sessions, and monthly for one group (#14).

#### 5.1.2 **Quality assessment**

The whole-study quality assessments are shown in Appendix B. The studies were of varied methodological quality, but there were reliable pieces of information relevant to this review extracted from all of them. For example, intervention #13 was an unsuccessful telephone peer support group that had very few participants and the reporting of the group itself was methodologically very low quality (Ludwick, 2017). This was, however, the only intervention that used a telephone group, and the local contextual factors (e.g. high local rates of perinatal mental health difficulties and comprehensive attempts to publicise the group) were well described. The only

point extracted for this review was therefore that group telephone support may not be an appealing format (see section 5.3.7 below).

# 5.2 Final theoretical model with empirical studies - introduction

# 5.2.1 **Three part theoretical model – take-up, use (positive) and use (negative)**

The final theoretical model is a refinement of the initial theoretical model (the hypothesised C-M-O configurations based on the literature reviewed in the exploratory phase of the review, presented in Chapter 4) in the light of the C-M-O analysis of the empirical studies.

The model is presented in three sections:

- A. Programme theories related to *taking up* peer support (contexts and mechanisms, where the outcome is take-up)
- B. Programme theories (contexts, mechanisms and outcomes) related to *how peer support works positively*
- C. Programme theories (contexts, mechanisms and outcomes) related to *how peer support works negatively*

Each section consists of the C-M-O theories presented first in a table, and then in narrative text. The tables show contexts (social or individual factors); mechanisms (the resources introduced by the peer support intervention and the reasoning or reaction of mothers to those resources); outcomes; the studies in which the C-M-O is evidenced; and illustrative quotations from those studies. In section A, only contexts and mechanisms are shown in the table as in each case the outcome is that the mother makes use of peer support.

# 5.2.2 **Reference to interventions or to studies**

In the narrative sections of the model, the 22 peer support interventions are referred to by the intervention numbers given in Table 4 above. The author and year of publication are used when reference is being made to the evidence reported in a specific article.

# 5.2.3 Labelling used in the model (Tables 5, 6 & 7)

Each C-M-O configuration has been given a theory number to facilitate cross-referencing between the tables and narrative (1-24 for positive theories, N1-10 for negative theories).

The contextual factors are labeled C-S for Context-Social and C-I for Context-Individual. The detail about the contextual factors that formed part of the initial theoretical model has been presented in Chapter 4 and the numbering (e.g. C-S1) refers to the numbering used in that chapter. Quotations are marked 'Counter' if they contradict the theory or indicate contexts in which the mechanism was not activated. Quotations are italicised if they are from a participant interview, and in normal font if they are the authors' summary.

# 5.2.4 Use of font to distinguish phases of the model

Differences in font (see Box 1) have been used to indicate the ways in which the model has evolved between the hypothesised initial theoretical model, and the evidenced final theoretical model.

# Box 1 Use of font to distinguish initial and final theoretical model (in Tables 5, 6 and 7)

**Normal font**: Programme theories which formed the initial theoretical model and were also present in the final model.

**CAPITALISED FONT**: Theories which were not in the initial theoretical model, but were added in the light of C-M-O analysis.

**Strikethrough:** Theories which were in the initial theoretical model, but for which no evidence was found.

# 5.3 Theoretical model section A: take-up of peer support

# 5.3.1 Introduction to section A

This section refers to Table 5 and describes the first part of the theoretical model, which focuses on the 13 context-mechanism configurations related to the outcome of the mother making use of peer support.

There was considerable variation reported in the proportion of mothers who took up peer support. Where support was offered directly, it was accepted by 37% of mothers in intervention #12 (telephone) and 52% of mothers in intervention #21 (face-to-face). Where mothers were invited to take part in a peer support trial, initial recruitment where reported ranged from 38% in intervention #18 (telephone) to 72% in intervention #6 (telephone). In intervention #18, recruitment problems led to the target recruitment for the trial being reduced from 70 to 30, and just 28 mothers were actually recruited. There were also unanticipated difficulties in recruiting mothers to receive peer support reported in interventions #8, 13, 14 and 17.

The studies generally did not investigate why their participants had decided to use peer support, although some had obtained information about the reasons why other mothers who were offered peer support had chosen *not* to use it. This came directly from the mothers for interventions #3, 6 and 18 (Cust & Carter, 2018; Dennis et al., 2009; Sembi, 2018), and via feedback from referrers for intervention #8. This means that, although there was evidence to support most of the contexts in

the initial theoretical model, linking these to the reasoning and resources of the participants that led to take-up mostly remained at the level of hypothesis.

	Contex	t	Mee	chanism	Studies	Example quotation
Theory #	Social level	Individual level	Resources provided by peer support programme	Reasoning or reaction leading to use of peer support		
1	<ul><li>C-S1 Cultural narratives of idealised motherhood</li><li>C-S2 Stigma of mental illness</li></ul>	<b>C-11</b> - Negative self- labelling as a uniquely abnormal 'bad' mother	Offer of peer support	Mother <u>believes</u> peers will be empathetically understanding and trustworthy	Duskin (2005) Sembi (2018)	<i>C: "I thought I was the only person in the world who must be feeling like this about my baby… I felt so guilty and I felt like I didn't dare say anything to anybody about the way I was feeling, because I thought people would think I'm a terrible person."</i> (Sembi, 2018)
2	C-S1 Cultural narratives of idealised motherhood C-S2 Stigma of mental illness	<b>C-12</b> Hides feelings from partner, family & friends & can't meet needs for authenticity in relationships, or lack of social network	Offer of peer support	Mother feels safe to attend because peers are outside normal social circle	Cust & Carter (2018) Duskin 2005) Sembi (2018)	C: "It was also about feeling like I should be giving my friends the impression that I felt great, everything was greatand I couldn't even summon up enough energy to carry a conversation with them." (Duskin, 2005) C-M: "You don't want to shock people by revealing some of your feelings and thought processes, it's very difficult. You couldn't perhaps confide in your husband as you would be able to someone on the phone." (Sembi, 2018) COUNTER: "The women [who turned down peer support] also felt that they may be uncomfortable talking to a stranger, and that they were not sure if it would really offer any benefit to them." (Cust & Carter, 2018)

# Table 5 Theoretical model section A: context-mechanism configurations where the outcome is take-up of peer support

	Contex	t	Med	chanism	Studies	Example quotation
Theory #	Social level	Individual level	Resources provided by peer support programme	Reasoning or reaction leading to use of peer support		
3	C-S1Cultural narratives of idealised motherhood C-S2 Stigma of mental illness C-S3 Expectation that new mothers will meet social support needs through other new parents	C-13 Mother lacks a social network C-14 Avoids new parent groups as these make her feel worse	Offer of peer support	Mother feels safe to attend because <u>believes</u> peers will be non-judgementally accepting	Anderson (2013) Duskin (2005)	C: "I hated regular mother's groups because I hear just how well they are doing Why am I so different than these other women? Why am I having such a hard time? What is wrong with me?" (Duskin, 2005) COUNTER: ""[The generic group] was sort of like fun and social. It was something to do while we're on maternity leave and a social outlet'After she disclosed her PPD experience, other group members began disclosing their own struggles with PPD." (Anderson, 2013)
4	<b>C-S4</b> Primary health professionals have limited training on perinatal mental health difficulties and limited time	C-15 Conceals symptoms from professionals – fear of judgment, consequences, lack of understanding / empathy; OR DISAPPOINTING PREVIOUS EXPERIENCE OF PROFESSIONAL SUPPORT	Peer support is available by self- referral	Mother <u>believes</u> peer support is a safe or better alternative, trusts lived experience over professional knowledge	Carter et al. (2019) Cust (2016) Eastwood et al. (1995) Lynch (2019) Sembi (2018)	C: "They said that a lot of good advice is given from a negative viewpoint by health visitors, which undermines what little confidence they have and either causes or emphasises guilt, and this makes them reluctant to share concerns." (Eastwood, 1995) C: "You're not a hundred percent honest with official people for fear of what might happen to your family You [need to] have built up a level of trust first and you haven't got time to do that with a GP, you've got ten minutes."(Sembi, 2018) C-M: "I find it difficult to talk to people who haven't been through things themselves [With my counsellor I asked] have you ever had any problems no? I was like, you're learning this out of a book then. How can you tell me that this is normal what I'm feeling if you've never felt it yourself?" (Sembi, 2018)

	Contex	t	Mee	chanism	Studies	Example quotation
Theory #	Social level	Individual level	Resources provided by peer support programme	Reasoning or reaction leading to use of peer support		
5	C-S4 Primary health professionals have limited training on perinatal mental health difficulties and limited time	C-I6 Mother trusts health professionals	Programme has good relationship with local health professionals and a simple referral process	Mother is referred by a health professional she trusts OR RECRUITED IN HOSPITAL	Acacia (2019) Carter et al. (2019), Chen et al. (2000) Cust & Carter (2018) Dennis et al. (2009) Letourneau et al. (2015, 2016) Lynch (2019) Pitts (1999) Sembi (2018) Shorey & Ng (2019)	M: "Acacia's longevity and excellent reputation can in part be attributed to our active partnership work, which has helped to embed our services across local perinatal mental health pathways. We are active participants in all of the Birmingham-based groups and networks for perinatal mental health." (Acacia, 2019) C: "We sought feedback from the community midwives as to why recruitment was difficult: 'We simply do not have time to take on this additional role."" (Cust, 2018)
6	<b>C-S5</b> Different conceptions of mental health difficulties and appropriate response	<b>C-17</b> Personal conception of cause and meaning of perinatal mental health difficulties	Programme terminology matches mother's own understanding of her mental health	Mother <u>believes</u> that the peer support is aimed at people like her	Duskin (2005) Sembi (2018)	C: "Even back then, I would not have thought I was depressed, I just thought, I'm having a tough time." (Duskin, 2005) C: "When I initially went to my GP I felt very apologetic that I was wasting time, because it's not a visible illness or anything." (Sembi, 2018)
7	<b>C-S6</b> Public health campaigns promote message 'it's good to talk', but there are differences in acceptability of talking to outsiders	<b>C-18</b> Mother believes it is useful and acceptable to talk about mental health difficulties	Offer of peer support	Mother wants to talk about her mental health	Shorey & Ng (2019)	C: "However, mothers [in Singapore] are often dissatisfied with social support, especially due to the lack of emotional support received. This can be attributed to the conservative nature of Asian societies in which direct emotional expressions are often discouragedThis highlights an unspoken need for more emotional support for Asian mothers. Mothers often mentioned a need for a close, nonjudgmental confidante to initiate support and empathize with them." (Shorey & Ng, 2019)

	Contex	t	Me	chanism	Studies	Example quotation
Theory #	Social level	Individual level	Resources provided by peer support programme	Reasoning or reaction leading to use of peer support		
8		<b>C-19</b> Mother has preference for cultural homogeneity or heterogeneity	Programme is able to offer a choice in cultural matching or otherwise	Mother feels safe to attend because similarity or difference matches her needs	Shorey & Ng (2019)	C-M: "In order to increase relevance to self, mothers generally preferred to be matched with a volunteer of similar age, same ethnicity, employment status, marital status, recency of childbirth, and similar ages of children." (Shorey & Ng, 2019)
9	<b>C-S7</b> Limited access to perinatal mental health support, including long waiting lists	C-I10 Mother wants counselling	Programme positions self as alternative for those who do not meet criteria for professional support	Mother may go to peer support as a holding position while waiting for counselling or hoping she will receive counselling-type support	Carter et al. (2019) Eastwood et al. (1995) Letourneau et al. (2015)	C: "There doesn't appear to be a lot around unless you are actually feeling completely suicidal." (Carter et al., 2019) COUNTER: "They perceived peer-support to be a different type of support from professional support and, as such, should sit alongside professional support, but not replace it." (Sembi, 2018)
10	<b>C-S8</b> Social norm that mother is primarily responsible for meeting baby's needs alongside domestic responsibilities and other work	C-I11 Mother has resources of time and/or money to invest in meeting her own needs	Programme offers support requiring less commitment e.g. by phone or drop in group OR PROVISION OF CRECHE / TRANSPORT, OR AT ACCESSIBLE LOCATION/AT HOME	Mother can use peer support in ways that do not exceed her resources	Cust (2016) Carter et al. (2019) Dennis (2010) Eastwood et al. (1995) Fairbairn & Kitchener, (2020) Field et al. (2013 a/b) Letourneau et al. (2016) Lynch (2019) Prevatt et al. (2018)	M: "I think when we're feeling very low energy and sad, it's very hard to force ourselves out of the home. So the phone could be your best friend, or could be the best way of getting that support." (Letourneau et al. 2016) COUNTER: "It would have been nice to talk some more, but it is very hard to find the time with a new baby." (Dennis, 2010) "The initial recruits declined to be involved Their reasons were varied but included still being in the workplace, and subsequently not having enough time to receive the support." (Cust & Carter, 2018)

	Contex	t	Me	chanism	Studies	Example quotation
Theory #	Social level	Individual level	Resources provided by peer support programme	Reasoning or reaction leading to use of peer support		
11		<b>C-I12</b> Low social confidence	Programme offers choice of 1:1 or group support	Mother feels safe talking to a peer supporter 1:1 although would not feel safe in peer support group <del>, or vice</del> <del>versa</del>	Dennis (2010) Fairbairn & Kitchener (2020) Pitts (1999) Sembi (2018)	C-M: "Sometimes a one-to-one situation could have helped as there were some things I felt I could never say to complete strangers." (Pitts,1999)
12	<b>C-S10</b> TELEPHONE WIDELY USED BY TARGET COMMUNITY TO ACCESS HEALTH SERVICES	C-115 MOTHER SEES TELEPHONE SUPPORT AS CONVENIENT AND/OR PREFERS ANONYMITY	PROGRAMME OFFERS TELEPHONE SUPPORT	MOTHER IS COMFORTABLE USING TELEPHONE FOR SUPPORT	Dennis (2010) Letourneau et al. (2016) Sembi (2018) Shorey & Ng (2019)	C-M: "I just found myself telling her things that I wouldn't tell other peoplebecause there's no face there, there's no actual person there. It does feel really private." (Sembi, 2018) COUNTER: "I didn't feel I could talk over the phone to someone I didn't know well." (Sembi, 2018) COUNTER: "Mothers and peer volunteers were highly in favor of at least one session of face-to-face meet- up, which would allow easier rapport building." (Shorey & Ng 2019)
13	<b>C-S9</b> Pool of potential peer support volunteers exists in community		There is a peer supporter available to start support and to continue it reliably when the mother needs it.	Mother can use peer support when she needs it.	Cust (2016) Cust & Carter (2018) Dennis (2010) Sembi (2018)	<ul> <li>M: "As the recruiters, we need to provide further specification as to how time consuming the [volunteer] role may potentially be." (Cust &amp; Carter 2018)</li> <li>M: "I've not been available myself and she's been struggling with her family to be able to call when it was appropriate for both of us." (Sembi, 2018)</li> </ul>

#### 5.3.2 Theories 1, 2 & 3: Shame and concealment

Most of the studies referred in general terms to the experience of postnatal depression as alienating and incorporating a sense of failure in the context of social norms of contented motherhood. Duskin (2005) and Sembi (2018) explored these feelings in detail for mothers who had taken up peer support in interventions #7 and 18. They confirmed the loneliness and shame in the mothers who believed that they were uniquely failing, concealment from family and friends, and (in #7) inability to meet the need for 'new mother' social relationships at generic new parent groups. However, it cannot be assumed that all mothers prefer to talk to someone outside their social circle: some mothers who declined in intervention #3 said they would not be comfortable talking to a stranger.

In addition, not all mothers with perinatal mental health difficulties shared the aversion to generic new parent groups. Anderson's study (2013) included 16 mothers with postnatal depression who attended generic new parent groups alongside seven mothers who attended peer support groups (#1), and reported that some enjoyed attending generic groups because they found genuine social support and validation of the struggles of motherhood. Although she argued that generic groups may 'mute' mothers with postnatal depression from talking about their mental health, her study also highlighted the experiences of two participants who disclosed their mental health difficulties at generic groups, which led to other mothers reciprocally disclosing their own postnatal depression, and a spontaneous peer support dynamic.

#### 5.3.3 **Theory 4 & 5: Primary health professionals**

Several UK studies referred to mothers' reluctance to be honest about their mental health with primary health professionals. For example, some mothers in intervention #18 feared being seen as not coping, and did not want to expose themselves to judgement or to safeguarding proceedings; while others worried about being seen as wasting health professionals' time about something unimportant. Lack of time to build a trusting relationship with busy health professionals exacerbated these fears. Paradoxically, in some of these UK interventions, the mothers had either all (# 2,3) or mostly (#18) been referred to the peer support by health professionals, so a degree of disclosure must have already taken place. It may be that a disappointing experience of professional support was a motivating factor in taking up peer support for some of these mothers, who trusted lived experience over health professionals' knowledge (#18). The possibility of peer support as a safe *alternative* to disclosure to health professionals was illustrated by the community organisations where women could also access the support by self-referral (#20-22).

In many of the time-limited interventions, mothers were referred by health professionals or recruited through maternal health services (#2-4,6,12,16,18,19), highlighting the importance of close

working relationships with local health professionals. The straightforward referral of postnatal mothers by health visitors in intervention #2, where the researcher was herself a practising health visitor, contrasted with the extensive recruitment problems experienced in intervention #18, which initially and unsuccessfully relied on health visitors. Recruitment problems experienced in intervention #3 and 14 demonstrated how health professionals might be enthusiastic about peer support in principle but then face other barriers (such as lack of time) to making referrals, reinforcing the importance of an easy referral process. Even when substantial efforts were invested in building relationships with health professionals to advertise the peer support (#3,13,18), these could be thwarted by contextual factors related to capacity in the local maternity service. By contrast, where a community organisation was active in the local area for a long time, its peer support offer could become embedded in local care pathways (#20).

## 5.3.4 **Theories 6 -8: Cultural background and perspectives on mental health**

Most studies included some demographic information about participants. Where ethnicity was reported, most from the UK or North America indicated that the great majority (#11,17) or all (#2,22) of their participants were White. Ethnicity was not reported for intervention #6 but 21% of mothers and 54% of volunteers described their nationality as non-Canadian. The outliers were interventions #9 and 10 in the USA, in which predominantly Hispanic and African-American mothers were recruited at ultrasound clinics to two parallel arm trials where peer support was compared to either interpersonal therapy or yoga. In Taiwan (#4), the peer support group was used by Chinese women, and in Singapore (#19), English-language telephone support was used by mostly Chinese and Malay women.

There was little evidence for the hypothesised mechanism of the programme's self-description matching the mother's own understanding of perinatal mental health difficulties, although in interventions #7 and 18 there were examples of mothers not identifying their depressive feelings as depression, or not believing that it was legitimate to seek help for those feelings. None of the studies reported how the programmes had described their offer to potential users of the peer support. It was notable that some interventions offered by community organisations allowed mothers to self-define their perinatal mental health and their need for support (#1,14,20,22), whereas most of those led by health professionals or carried out as part of an RCT used a formal screening tool to assess eligibility. This different approach may have reflected a different emphasis or language about how perinatal mental health peer support was described.

Shorey and Ng (2019) reflected on the differences between "individualistic Western culture" and "collectivistic Asian culture" in which direct expressions of emotions are discouraged (#19). They

noted that in Singapore new mothers are often dissatisfied with the social support they receive from family or in-laws during the first month after birth, because although there is a high level of practical support it lacks the emotional dimension that they need. In addition, mothers may experience stress as a result of conflict with in-laws over parenting style or beliefs, but feel inhibited from expressing their emotions out of respect for elders. The relatively low take-up of peer support in intervention #19 might be linked to these cultural inhibitions about expressing emotion, but might also plausibly be explained by the timing of recruitment in that study, very soon after birth.

Two of the community organisations (#20,21) demonstrated a flexible approach to offering peer support in contexts where some local mothers might not endorse the cultural narrative of 'it's good to talk'. As well as empathetic listening, Bluebell Buddies gave more holistic support such as advocacy and support with accessing other local services (#21). Acacia offered its peer support alongside practical options such as in-home help, and ran a specific programme to raise awareness of perinatal mental health among local Asian communities (#20). In intervention #11, emotional peer support given by telephone was compared with practical and emotional support given in the home by non-peer doulas who helped with childcare, light housekeeping and errands. Mothers receiving the doula support were more satisfied and Gjerdingen et al. (2013) suggested that this could be attributable to the practical nature of the support, but possibly also to its location, the greater training and experience of the doulas, or to the vastly higher average amount of time spent supporting (1.06 hours of peer support vs 23.4 hours of doula support).

Only in intervention #19 was there reference to mothers' preference (in Singapore) to receive peer support from someone of the same cultural background. In intervention #6, mothers were offered the option of a volunteer matched on ethnicity, but none of the articles reported how many mothers chose this.

#### 5.3.5 Theory 9: Mother actually wants professional support

There was little directly reported about the hypothesised scenario of mothers who go to peer support because a more formal mental health intervention is not available to them. There were hints that mothers in interventions #3, 9 and 10 did not have access to any formal alternative, and Letourneau et al. (2015) reported that some mothers left intervention #12 when they began to receive counselling. By contrast, the mothers in intervention #18 believed that peer support was not a substitute for health professional support, which may have been connected to the high proportion of interviewees who were receiving both kinds of support simultaneously.

#### 5.3.6 Theory 10: Overcoming barriers

Where socio-economic status or education were reported, in most of the interventions the majority of mothers were socio-economically advantaged and/or had completed post-secondary education (#2,5-7,11,12,19), although there were no significant differences between mothers who participated in the trial in intervention #5 and mothers who declined. The mothers taking part in groups in interventions #4 and 8 were more socially mixed, and the mothers participating in interventions #9 and 10 were primarily from low income backgrounds and had only a high-school education. In interventions #9 and 10, potential financial barriers to access were addressed by offering mothers \$30 (#9) or \$20 (#10) to pay for childcare and transport each time they attended a 20 minute peer support group. In interventions #8 and 15, groups were at a central location accessible by public transport. Intervention #15 offered childcare, and in intervention #8 groups were held in the evening to enable mothers to attend when their partners could take over the childcare. In interventions #2, 3 and 21, one-to-one meetings were held at the mother's home or other place of her choice. In intervention #22, transport and a crèche were initially offered to mothers from a largely rural area attending their centrally located peer support group, but the crèche was not financially sustainable and the transport offer was discontinued when the support moved to more local groups (Happy Mums staff, personal communication, 21.10.20).

It is difficult to draw clear inferences about the timing of the offer of peer support, which ranged from pregnancy (#3,9,10), 0-2 weeks after birth (#6,11,19), 6-12 weeks after birth (#2,4,5), and otherwise periods up to 24 months after birth or not stated. It may be more difficult for pregnant women who are still at work to make use of peer support (#3,10), but some mothers believed it would be better to establish a peer support relationship before birth (#19).

## 5.3.7 Theories 11 & 12: Format of support

None of the interventions offered mothers a choice of group or one-to-one format. There was little exploration of mothers' preferences, except interventions #6 and 18 where 64-68% of mothers offered one-to-one telephone support said they preferred this to (hypothetical) group support. Some mothers indicated that a group format could sometimes be stressful and limit disclosure (e.g. #16), and this may have deterred other mothers from taking up support.

Where peer support was offered by telephone, this could have both advantages and disadvantages for take-up, depending on the context. Some mothers found telephone support convenient (#6, 18), and it might overcome financial barriers such as the cost and inconvenience of transport and childcare (#12,18), or the cultural non-acceptability of seeking support (#19). Stakeholders identified the telephone-based approach as the most positive aspect of intervention #12, believing it overcame

barriers to access such as low energy and stigma, and some of the mothers in intervention #18 also liked the anonymity of telephone support, particularly if they were not matched with a mother from the same geographical area. In the most recent study included in this review (#19), mothers who were supported in the early postnatal weeks had a preference for support through text and WhatsApp messages, as these were easier to manage when their baby's needs were unpredictable.

By contrast, some mothers found telephone support to be an intrusion into busy life (#11), and said it was difficult to arrange peer support calls at times that worked for both their families, or they felt uncomfortable bothering an individual volunteer who was busy with her own children (#18). When offered the statement 'I like the support over the telephone', 18.5-27% of mothers in interventions #6 and 18 disagreed. Some of the mothers and volunteers in intervention #6 organised face-to-face meet-ups outside the parameters of the telephone intervention, and mothers in intervention #19 wanted to do this to build the peer support relationship.

Letourneau et al. (2016) and Shorey and Ng (2019) argued that telephone peer support may be particularly acceptable in contexts where telehealth is widespread, such as in a Canadian province with a large rural population where there was a well-established telecare helpline that served as the primary referral route (#12), and in Singapore, where the Smart Nation initiative has encouraged health care sectors to adopt telehealth (#19). The recruitment problems experienced in intervention #13, where a well-advertised telephone peer support group had minimal take-up in an area of high need and long wait times for mental health services, may indicate that group support offered by telephone is a particularly unappealing format.

# 5.3.8 Theory 13: Volunteers

Where peer support was provided by volunteers, recruitment, training and retention were fundamental to being able to offer timely support to mothers. Only one intervention (#3) had problems recruiting peer supporters with time to commit to their volunteering. The volunteer training in all interventions was brief, 0.5-2 days. This reflects beliefs that brevity was important to prevent professionalisation (#2,3,6); or that longer training would be too onerous (#12). Where a model was replicated, the training tended to be longer than in the original intervention, reflecting an experience or belief that the original training did not prepare volunteers adequately (#3,12,18).

The peer support interventions had varied expectations of their volunteers and varied experiences of retention. In intervention #6, 87% of those who trained started volunteering, and all were retained for the 12 week programme, during which they supported an average of two mothers each. There was no expectation imposed about the number of mothers a volunteer would support: "We

did not want to burden the peer volunteers – some would like the experience and some would not and they were able to stay in the program as long as they followed our protocols" (Dennis, 2014, p. 5). In intervention #2, all those who trained went on to volunteer and each supported two or three mothers for six weeks (F. Cust, personal communication 01.03.20); in intervention #19, 95% of those who trained started volunteering, and each supported at least three mothers for at least four weeks. Rates of attrition were much higher in intervention #18, where out of 19 peer supporters who trained, 13 left the programme after supporting none or one mother, leaving six (32%) who each supported 'up to four' mothers for four months.

Support and supervision for volunteers might affect how long they remained with the intervention (as well as affecting the quality of their support, relevant to sections B and C of the theoretical model below). Where this was reported, this support was varied in intensity and format, for example weekly group meetings or individual sessions as requested (#3); a monthly group and fortnightly individual face-to-face sessions (#2); occasional telephone/email support from the volunteer co-ordinator as needed, and volunteer meetings (#6); or telephone supervision from a clinical psychologist or the volunteer coordinator (#18).

# 5.4 Theoretical model section B: how peer support works positively

#### 5.4.1 Introduction to section B

This section refers to Table 6, and describes the second part of the theoretical model, focused on the 13 positive C-M-O configurations once the mother makes use of peer support. There was evidence for most of the positive theories in the original theoretical model, and the final theoretical model also contains some additional theories that were not anticipated. It was, however, rare to find full C-M-O configurations evidenced in the included studies. Generally there was evidence for mechanisms, sometimes linked to outcomes, while the contexts were often implied (or needed to be inferred) rather than stated.

	Context 'in what circumstances?' and 'for whom?'	Positive mechanism 'what is it that wor		Outcomes 'does it work?' and 'in what respects?'	Studies	Example quotations
Theory #		What happens during peer support	Reasoning or reaction of mother			
14	C-S1Cultural narratives of idealised motherhood C-S2 Stigma of mental illness C-S3 Expectation that new mothers will meet social support needs through other new	Mother talks honestly and is listened to empathetically	Feeling understood	Emotional release: able to share true self	Anderson (2013), Carter et al. (2019) Chen et al. (2000) Cust (2016), Dennis (2010), Duskin (2005), Eastwood et al. (1995) Montgomery et al. (2012), Pitts (1995) Prevatt et al. (2018)	<ul> <li>M-O: "Being able to cry and laugh with a group of very understanding women was a great release."</li> <li>(Pitts, 1999)</li> <li>C-M-O: "It was a release I'd be able to go and moan to and get everything off my chest I feel like you have to put on a brave face, like with my husband and my family and pretend everything is fine." (Sembi, 2018)</li> </ul>
15	parents <b>C-I1</b> Negative self- labelling as a uniquely abnormal 'bad' mother <b>C-I2</b> Hides feelings from partner, family & friends & can't meet needs for authenticity in relationships, or lack of social network	Mother talks honestly and is listened to non- judgementally	Feeling accepted by others, leading to self-acceptance	Improved self-esteem / self-concept Mother gains confidence to disclose to partner/family/friends and authentic relationships are restored Mother gains confidence to attend 'normal' new parent groups	Sembi (2018) Carter et al. (2019) Dennis (2003, 2010) Duskin (2005) Pitts (1999) Prevatt et al. (2018), Sembi (2018) Shorey & Ng (2019)	M-O: "I told you the scariest, worst, horrible, darkest, deep feelings that I felt, and it was like nobody batted an eye. And not only did nobody bat an eye, I got loving, patient, warm, understanding It just made me feel like, wow, I am a normal person." (Duskin, 2005) M-O: "Some expressed that, with encouragement from the group, they started to attend mother and toddler groups, where they have made further friendships." (Pitts, 1999)
16	C-I3 Mother lacks a social network C-I4 Avoids new parent groups	Peers give positive feedback about her feelings and actions	Feeling affirmed	Improved self-esteem / self-concept	Dennis (2003, 2010) Duskin (2005) Sembi (2018)	M-O: "I got validation that it was okay to feel depressed." (Duskin, 2005) M: "Told me that I did something wellAgree or strongly agree, 72.9%." (Dennis, 2010)

# Table 6 Theoretical model section B: positive C-M-Os for mothers using peer support

	Context 'in what circumstances?' and 'for whom?'	Positive mechanisms 'what is it that works?' and 'why?'		Outcomes 'does it work?' and 'in what respects?'	Studies	Example quotations
Theory #		What happens during peer support	Reasoning or reaction of mother			
17	C-S1Cultural narratives of	Peers talk about	Mental health and	Improved self-esteem /	Anderson (2013)	C-M-O: "It was the most helpful part of my
	idealised motherhood	their own	parenting	self-concept	Chen et al. (2000)	recovery. I spent most of my time believing I was
		perinatal mental	challenges are		Cust (2016)	useless and not a very good mother for not being
	C-S2 Stigma of mental	health and	normalised		Dennis (2010)	ecstatic about the birth of my child, talking to all of
	illness	parenting			Duskin (2005)	the others made me realise I was normal." (Pitts,
		challenges			Montgomery et al.	1999)
	C-S3 Expectation that		Compares herself to	Hope for recovery	(2012)	
	new mothers will meet		peers who are now		Pitts (1999)	M-O: "When I first attended it was nice to see
	social support needs		well		Prevatt et al.	women who were already getting better so I knew
	through other new				(2018),	there was light at the end of the tunnel." (Pitts,
	parents				Sembi (2018)	1999)
	C II No setting and		Compares herself to	Sense of perspective		
	C-I1 Negative self-		peers who are less			M-O: "I was like, wow, she's feeling exactly the
	labelling as a uniquely abnormal 'bad' mother		well			way that I felt, so I have done some progress
	abnormai bad mother					<i>because I don't feel that way anymore."</i> (Duskin, 2005)
	C-I2 Hides feelings from		Compassion for			
	partner, family & friends		others promotes			C-M-O: "When the mothers felt judgmental and
	& can't meet needs for		self-compassion			pessimistic about there [sic] own situations,
	authenticity in					through social comparison they were able to view
	relationships, or lack of					a woman in a similar situation with compassion
	social network					and objectivity and then to alter their negative view of themselves." (Duskin 2005)
	C-I3 Mother lacks a social					
	network					
	C-I4 Avoids new parent					
	groups					
	Context 'in what circumstances?' and 'for whom?'	Positive mechanism 'what is it that work		Outcomes 'does it work?' and 'in what respects?'	Studies	Example quotations
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Theory #		What happens during peer support	Reasoning or reaction of mother			
18	C-116 MOTHER TRUSTS PERSONAL EXPERIENCE OVER PROFESSIONAL KNOWLEDGE	Peers share ideas about self-care, coping with perinatal mental health, parenting, medication, mental health services, other community services	Mother gains information she finds credible and encouragement to try new things	Increased coping strategies and lower stress Increased take-up of mental health services Increased use of other community services	Chen et al. (2000) Cust (2016) Dennis (2003/2010) Duskin (2005) Fairbairn & Kitchener (2020) Montgomery et al. (2012) Pitts (1999) Prevatt et al. (2018) Sembi (2018)	M-O: "Women identified individual mothering challenges and solicited remediating information The group created a repertoire of practical mothering strategies." (Montgomery et al., 2012) C-M: "The mothers viewed their [peer supporter] as 'an expert' – [she] had experienced what they were currently experiencing and 'had survived' - therefore any guidance and advice that they could offer 'was tried and tested.'" (Cust, 2016) O: "Attendees responded that the program prompted the initiation of treatment." (Prevatt et al., 2018)
19	<b>C-S7</b> Limited access to perinatal mental health support, including long waiting lists	Peers use therapeutic techniques such as <del>reframing,</del> <del>challenging negative cognitions,</del> ENCOURAGING SELF-CARE	Mother experiences therapy-lite Mother gains access to techniques she can try	Increased coping with perinatal mental health difficulties	Sembi (2018)	M-O: "She was really good at suggesting I go and do something really nice for myself. Just to remind myself to do little things for me and to actually set a timescale." (Sembi, 2018) COUNTER: "The [volunteers] simply wanted to provide support to the women as a fellow 'mother to mother'." (Cust & Carter, 2018)
20	<b>C-I13</b> Mother is sufficiently well to give as well as receive peer support	Opportunity for reciprocal support	Mother offers support to other mothers in a group	Self-esteem Finding meaning in own experiences	Anderson (2013) Duskin (2005) Montgomery et al. (2012)	C-M: "Knowing that I was doing better and being able to share that with people, was important from the point of view of being able to reach out to them the way people had reached out to me." (Duskin, 2005)

	Context 'in what circumstances?' and 'for whom?'	Positive mechanism 'what is it that work		Outcomes 'does it work?' and 'in what respects?'	Studies	Example quotations
Theory #		What happens during peer support	Reasoning or reaction of mother			
21	C-I14 Mother has low self-esteem	Programme offers support from volunteers who are not paid for their time	Mother experiences herself as worth another person's time	Self-esteem Feels cared about	Acacia (2019) Shorey & Ng (2019)	M-O: "The main thing I remember was feeling that finally someone cared, [peer supporter] showed that she and others cared whether I was here or not." (Acacia, 2019) COUNTER: "I just felt like I was an extra burden for [the volunteer] she was busy with her own life." (Sembi, 2018)
22	C-I3 Mother lacks a social network	Same peers attend group over time, or 1:1 peer supporter is well matched Peer support is for mothers whose mental health difficulties are specifically connected to having a baby, and are mild-to	Mother forms meaningful relationships (that may continue outside group)	Reduced loneliness Increased social network	Dennis (2003/2010) Duskin (2005) Lynch (2019) Pitts (1999) Prevatt et al. (2018) Sembi (2018) Shorey & Ng (2019)	C-M-O: "A sense of belonging that I had lost because I had isolated myself from my old friends." (Duskin, 2005) M-O: "The women described the positive impact of accessing support, warmth and meaningful friendships with women who had/have shared experiences as transformative." (Lynch, 2019) M: "She sounded very similar to me on the phone even down to like sense of humour and things like thatSo I feel that that match there was absolutely brilliant." (Sembi,2018) COUNTER: "I didn't feel that we were particularly matched other than that we'd both had postnatal depression." (Sembi, 2018)

	Context 'in what circumstances?' and 'for whom?'	Positive mechanism 'what is it that work		Outcomes 'does it work?' and 'in what respects?'	Studies	Example quotations
Theory #		What happens during peer support	Reasoning or reaction of mother			
23	C-S8 Social norm that	PEER SUPPORT	PEER SUPPORT IS A	MOTHER GAINS	Duskin (2005)	C-M-O: "When you are depressed it is very hard to
	mother is primarily	SESSIONS ARE	REASON TO LEAVE	STRUCTURE TO HER	Pitts (1999)	get organised and you tend just to stay at home
	responsible for meeting	HELD REGULARLY	THE HOUSE	WEEK		feeling worse. This group made me get organised
	baby's needs alongside			SENSE OF ACHIEVEMENT		and gave me something to look forward to!" (Pitts,
	domestic responsibilities			IN MANAGING TO		1999)
	and other work			ATTEND		
24		GROUP PROVIDES	PEER SUPPORT	MOTHER HAS TIME FOR	Lynch (2019)	C-M-O: "The crèche is not viewed as a 'bolt on' or
	C-I17 MOTHER FEELS	CHILDCARE OR	REPRESENTS A	HERSELF	Pitts (1999)	'nice to have' by most service users but rather as
	TRAPPED AT HOME WITH	HELD AT TIME	BREAK FROM			crucial to the successful delivery of outcomes. For
	BABY	WHERE MOTHER	CHILDCARE			many women the time they use crèche is the only
		GOES ALONE				time they take away from their children and this
						time spent on self-care (even if it's not very much)
						is essential to their improved wellbeing." (Lynch,
						2019)
	?	1:1 support	?	Reduction in self-report	Chen et al. (2000)	
				depression scores	Cust (2016), Dennis	
		Group support			(2003)Dennis et al.	
					(2009), Field et al.	
					(2013 a/b)	
					Gjerdingen (2013)	
					Sembi (2018)	See narrative section 5.4.8
					Shorey et al. (2019)	4
	?	1:1 support	?	Non-significant reduction	Dennis et al. 2009	
		Crown automat		in self-report anxiety	Field et al. (2013	
		Group support		scores	a/b)	
					Shorey et al. 2019 COUNTER:	
					Eastwood et al.	
					(1995)	

#### 5.4.2 **Theories 14 – 17: Empathetic listening, acceptance, affirmation and normalisation**

As predicted by work on peer support in different contexts, across all interventions there was very strong evidence for peer support as a means of overcoming shame and stigma (Goffman, 1963) through emotional and appraisal social support leading to emotion-focused and perception-focused coping (Cohen & Wills, 1985). Mothers experienced empathetic understanding from peers, which they sometimes contrasted with the formulaic responses of health professionals who did not have lived experience. This enabled them to experience the emotional release of speaking about their difficult feelings. Their disclosures were received compassionately and non-judgmentally, and they received positive feedback about their feelings and actions. This acceptance and affirmation enabled mothers to see themselves as worthy of acceptance and encouraged further self-disclosure (Rogers, 1956). Many mothers in intervention 6 chose to speak to their peer supporter only a few times and Dennis (2010) drew attention to the value of *perceived* support (i.e. knowing the support was available, even if they did not use it); but another possibility is that having experienced an initial emotional release, they did not feel the need to repeat it. Shorey and Ng (2019) argued that the suppression of emotional expression in Asian cultures gives peer support a culturally-specific role in filling mothers' unmet needs for emotional support within a non-judgemental, empathetic relationship.

Another strongly evidenced strand of peer support across most programmes was hearing other women talk about their perinatal mental health and parenting challenges, which normalised what mothers had previously believed to be a highly abnormal experience, and enabled them to practise greater self-compassion (Neff, 2003). Lateral social comparison (Festinger, 1954) helped to overcome their sense of unique 'failure' based on their poor mental health, their experience of not loving their baby, and their self-blame for their babies' crying or lack of sleep. In intervention #18 the reassurance from a peer that these were common experiences was explicitly described as more credible than the same reassurance from a health professional.

There was also some evidence of upward social comparison (hope for recovery) and downward social comparison (gaining perspective and a sense of progress). Duskin (2005) identified two ways in which normalisation might be expressed through the 'normative narrative community' (Rappaport, 1994) of a peer support group (#7): "they were able to shift the blame from themselves as inadequate mothers to the disorder of postpartum depression. So simultaneously postpartum depression seemed to be normalized as a reasonable response to having a baby and their experiences were normalized as a common expression of postpartum depression" (Duskin, 2005, p.162). She also commented that it may be socially unacceptable for women to admit to making

themselves feel better by contrasting themselves with another woman's unhappiness, so downward comparison may be experienced more frequently than it is reported.

The use of the validated Peer Support Evaluation Inventory provided insight into how these peer support mechanisms may not work in the same way for all women. In intervention #6, over 90% of mothers agreed or strongly agreed that their peer listened, accepted them for who they were, and helped them to feel they were not alone in their situation. However, a small number of mothers (8%) did not agree that they felt accepted by their peer, and only 62% agreed that "With my peer I could confide my most inner feelings". Over 90% of mothers agreed or strongly agreed that their peer helped them to feel they were not alone in their situation and that what they were going through was 'normal', but only 58% agreed that "My peer revealed personal information". 80% said that they felt more similar to other mothers after the peer support, but only 57% said that their peer supporter had helped them feel that way. Of the mothers who said that over the past couple of months they had a more positive attitude towards themselves, fewer than half attributed this to their interaction with their telephone peer supporter.

There was no evidence for the hypothesised programme theory that mothers' improved selfconcept would enable them to disclose their mental health to their partner, family or friends where this had not already happened. There was limited evidence that improved self-concept gave some mothers the confidence to start attending 'normal' new parent groups without a perinatal mental health focus (#2,16,18). By contrast, the exit strategy from a time-limited group run by health visitors (#8) was not re-integration into the community, but for the depressed mothers to continue meeting together on their own.

#### 5.4.3 **Theory 18: Peers share ideas about self-care, coping, services**

Many mothers found it beneficial to hear peer experiences and advice about self-care and coping with mental health and parenting issues. This could be understood through the lenses of social learning theory (Bandura, 1977) and informational social support leading to problem-focused coping (Cohen & Wills, 1985). The particular credibility of peers was sometimes highlighted, their experiential knowledge (Borkman, 1976) contrasted with health professionals whose suggestions might be unrealistic (e.g. #18). Ninety per cent of mothers in intervention #17 said that participating in the group had affected their confidence as a mother very positively or positively, and 80% that it had affected their ability to manage their home.

In a few studies (e.g. #17) there was reference to peer support motivating or encouraging a mother to take up professional support. This could occur indirectly when peer support altered mothers'

perspectives through realisation that their own insecurities may have led them to misjudge health professionals' intentions in offering support (#18). Supporting mothers to access other local groups and services (including accompanying them) was a formal part of the paid peer support role in intervention #21.

The use of the Peer Support Evaluation Inventory again provides a corrective to assumptions about peer support working in the same way for all. Of the mothers in intervention #6 who said they were coping better, solving their problems, or responding better to stressful situations, fewer than half said that their peer supporter had helped them feel that way. In addition, there was no difference in health service utilisation between those in the intervention and control groups.

### 5.4.4 **Theory 19: Peers use therapeutic techniques**

There was no evidence in these studies for peers using therapeutic techniques to support mothers, other than urging self-care. This may reflect the brief training of peers in these interventions, and an explicit intention to avoid professionalising the support (#2,3,5,6).

### 5.4.5 Theories 20-21: Reciprocal support, gift relationship

Although it was clear that mothers were supporting each other within the peer support groups, there was less evidence than expected for helper-therapy (Riessman, 1965), with only brief allusions to this (#1,7,15). There was also limited implied reference to the psychological benefits of receiving the gift of a person's time in one-to-one interventions given by volunteers (#19,20). By contrast, one of the mothers in intervention #18 described receiving support from a volunteer as socially stressful, because, unlike a paid counsellor, the volunteer was fitting her peer support into a busy life and the mother worried she was a burden.

### 5.4.6 Theory 22: Meaningful social relationships

In both groups and one-to-one interventions, peer support was described as a social relationship that could overcome loneliness and create a new sense of belonging (Baumeister & Leary, 1995). For example, the peer support group in intervention #23 was reported to help overcome the triple isolation of mothers who lived in rural areas, were cut off from previous work or social opportunities by parenthood, and felt separated from others by their experience of poor mental health. Mothers felt an increased sense of belonging and community in peer support groups (#16,17), and some mothers continued these social relationships outside the groups (#7,16). Ninety-seven percent of mothers in intervention #17 agreed that while in the group they felt less isolated and 80% agreed that participating in the group had affected their social network positively. As these peer support

groups were reported to be generally socio-demographically homogenous, it is likely that this contributed to the successful formation of social relationships (Helgeson & Gottlieb, 2000).

One-to-one support could also help to overcome loneliness, although to a lesser extent: 82% of mothers felt less alone in intervention #6, and 58% attributed this to their peer support. The RCT showed no difference in measured loneliness between the control and intervention groups. In intervention #19, there was no statistically significant difference in loneliness between the intervention and control arms, although there was a positive trend in favour of the intervention arm, and some mothers used the language of friendship when talking about their peer volunteers. Overall these relatively weak social bonds did not suggest that theories of adult attachment (Eckenrode & Hamilton, 2000) were likely to be significant.

These results are likely to have been affected by the telephone format. Gjerdingen et al. (2013), Sembi (2018) and Shorey and Ng (2019) all suggested that building rapport may be much more challenging when only using telephone calls or messaging, compared with face-to-face (#11,18,19). Shorey and Ng (2019) observed that this had sometimes resulted in "awkwardness and one-sided, superficial relationships" (p. 8); they suggested that videoconferencing might be a solution.

There was some evidence about the matching process and individual peer supporters' personal qualities that enabled them to build relationships successfully: a common experience of perinatal mental health difficulties was not necessarily sufficient. In intervention #6, peer supporters were selected based on extroversion and communication skills and matched on ethnicity if desired. In intervention #12, volunteers and mothers were matched on language and, when possible, on age, number of children and other characteristics such as a military spouse. In intervention #18, matches were said to work best where they adhered to the intended criteria: age, number of children, level of education, hobbies and interests, and three words describing their own personality supplied by mothers and volunteers. In intervention #19 mothers preferred to receive peer support from someone of the same cultural background, age, employment status, marital status, and ages of children. By contrast, the volunteers in intervention #19 did not perceive cultural background as important, preferring to be matched on modes of birth and feeding, and socioeconomic and employment status. Shorey and Ng commented that building a trusting peer support relationship might take longer in their local context: "In a culture that emphasizes emotional restraint, avoidance of shame, and saving face, it may take a longer time for mothers to warm up and share their problems with volunteers" (2019, p. 10).

#### 5.4.7 **Theories 23-24: Other benefits of peer support groups**

There were some unanticipated theories that were not directly connected to the 'peer' nature of the support, but were spin-off benefits of some group models. Some mothers attending peer support groups felt they benefited from having structure to their week and a reason to leave the house (#7,16). Mothers in intervention #22 described the crèche as essential to their improved wellbeing because of the break it gave them from their children and the chance to focus on self-care. Some mothers found attending a group in itself provided this break (#16), which suggests that it legitimised an evening away from family responsibilities. These latter two theories point to the likelihood that, whereas flexible telephone support or in-home support may be more useful for some mothers because it is more convenient, for other mothers there are specific benefits from having a routine with a place to go and time set aside for themselves.

#### 5.4.8 Mental health outcomes of peer support using validated instruments

This section draws on the studies that used validated mental health scales to assess the measurable mental health impact of peer support interventions. On the evidence of this review it is not possible to claim that any particular C-M-O configuration leads to these ultimate mental health outcomes. It is possible that one or more C-M-O configurations may operate to improve the mental health of any individual mother, just as it is possible that negative C-M-Os may obstruct improvement in mental health outcomes or contribute to deterioration.

#### 5.4.8.1 **Depression - one-to-one support**

The two large RCTs of one-to-one telephone support (#6,19) found statistically significant improvements in the depression scores of mothers who received peer support. The biggest trial was of intervention #6, and this found that mothers in the peer support group were significantly less likely to have symptoms of postnatal depression at the 12 week assessment than those in the control group (odds ratio 2.1, 95% CI 1.38 to 3.20). There were no significant differences at the 24 week follow-up, which Dennis et al. (2009) attribute to the referral for treatment of all mothers identified as having symptoms above the clinical threshold at 12 weeks. The trial in intervention #19 also found a statistically significant difference in depression scores three months after birth after adjusting for covariates (d=-2.11; 95% CI -4.0 to -0.3; P=.03).

These trials confirm the results of smaller pilot studies of one-to-one support where findings consistently showed trends in depression scores favouring the intervention arm, although the statistical inferences that could be drawn were limited by small sample sizes (#2,18), wide confidence intervals (#5), and non-equivalent intervention and control groups (#11). Sembi (2018) acknowledged that it was impossible to extract the impact of intervention #18 on mental health

scores from the impact of the mental health treatments which most participants were also accessing. Intervention #12 was a quasi-experimental study of telephone support. This showed improvements in pre-test/post-test depression scores, but also indicated the fluctuating nature of postnatal mental health, with a finding that slightly more mothers receiving peer support were depressed at the end of the intervention compared with mid-point.

### 5.4.8.2 Depression - group support

The RCT in intervention #4 found that mothers who attended the four-week group had significantly decreased depression scores (t = -6.14, P < .01) immediately post-intervention, whereas there were no significant changes for mothers in the control arm. However, only half of the mothers who met the inclusion criteria were randomised; the reasons for this were not reported. When a peer support group was compared to an interpersonal psychotherapy group (#9) and yoga (#10), depression scores reduced equally for mothers receiving peer support as for those receiving the other interventions, contrary to the researchers' expectations. The quasi-experimental study of intervention #17 highlighted an interesting caveat through within-participant pre-post analysis: while there was a significant overall reduction in depression scores, the improvement in mental health was less for mothers who had an unplanned caesarean birth or had complications during pregnancy or birth. No other study carried out sub-group analysis that would indicate sub-groups of mothers who may benefit more or less than others.

#### 5.4.8.3 *Anxiety*

In contrast to the findings on depression, there was very little evidence from RCTs of positive impacts of peer support on anxiety scores. Some studies reported a non-significant trend favouring the intervention arm (#6,19), and there were equivalent reductions in anxiety for peer support compared with interpersonal psychotherapy (#9) and yoga (#10). In intervention #8, mothers' pre-test/post-test anxiety scores were little changed or in some cases increased; the authors link this to mothers' anxiety about the ending of the group and whether their planned self-led group might fail.

# 5.5 Theoretical model section C: how peer support works negatively

#### 5.5.1 Introduction to section C

This section refers to Table 7, and describes the third part of the theoretical model, which focuses on the eight negative C-M-O configurations once the mother makes use of peer support (and an additional two C-M-O configurations that were in the initial but not the final model). There was much less evidence for hypothesised negative C-M-O configurations. Where mothers' drop-out rates

from time-limited interventions were reported they were generally low (e.g. #9,10) or none at all (e.g. #2,3). Half of participants dropped out of intervention 18, and there was an unexpected finding that slightly more participants dropped out from the intervention group who received peer support telephone calls, than from the control group. Drop-out from peer support is not *necessarily* an indication of negative impact, as mothers might leave peer support for positive reasons (feeling better) as well as negative ones (not enjoying it or feeling worse), or for reasons unconnected to the peer support, such as work. Pitts (1999) reported a comment from a GP who was a referrer to intervention #16: "*the group helps some, while others are adamant it is not for them after one session*".

	Context	Negative mechanisms		Negative outcomes	Studies	Example quotations
Theory #		What happens during peer support	Reasoning or reaction of mother			
N1	C-112 Low social confidence	Attempts at friendship unsuccessful	Reinforces sense of social failure	Reduced social confidence and self- esteem		
N2	<b>C-I12</b> Low social confidence	Peer support becomes a safe bubble but mother is unable to move beyond it to authentic relationships with non-peers	Mother is distressed about ending of support that she relies on.	Anxiety about ending. Loss of social support. <del>Grief and sense of</del> <del>loss after ending.</del>	Carter et al. (2018/201 9) Cust (2016) Eastwood et al. (1995)	M-O: "I dreaded my visits ending, I was really going to miss this support." (Carter, 2019) M-O: "The [volunteers] were concerned that they were providing short-term, intensive support and then withdrawing and they worried about whether, after having such support, that the women's postnatal depression may be exacerbated once this was terminated." (Carter, 2018)
N3	<b>C-I14</b> Low self- esteem and low internal locus of control	Peers talk about their own perinatal mental health and parenting challenges but do not validate others' experiences and feelings Programme has inclusive approach and the mothers are not similar in background or mental health experience	Mother feels unvalidated, abnormal.	Increased sense of abnormality and shame Loss of authenticity	Carter et al. (2018) Dennis (2010)	M-O: "While blatantly negative effects were rare in this trial, almost 10% of mothers reported that the peer minimized their problems." (Dennis, 2010) M: "[The volunteer] confessed that although she did want to provide all of the right support to her allocated mother, she also wanted to: <i>take control</i> <i>and tidy the mother and her house up.</i> " (Carter, 2018)

# Table 7 Theoretical model section C: negative C-M-Os for mothers using peer support

	Context	Negative mechanisms		Negative outcomes	Studies	Example quotations
Theory #		What happens during peer support	Reasoning or reaction of mother			
N4	<b>C-I14</b> Low self- esteem and low internal locus of control	Peers talk about their own perinatal mental health and parenting challenges	Mother feels bad about not coping when others are worse, or fear of getting worse	Self-criticism / reduced emotional wellbeing	Cust & Carter (2018) Duskin (2005) Pitts (1999) Prevatt et al. (2018)	M-O: "She made me really anxious because it didn't seem like she was getting any better back to my old fear, am I never going to get better?" (Duskin, 2005) M-O: "(H)earing about things that all of the other moms worried about made me more anxious. That's why I personally only attended one meeting." (Prevatt, 2018)
N5		Peers talk about their own perinatal mental health and parenting challenges	Mother feels discouraged that others are getting well more quickly	Self-criticism / reduced emotional wellbeing	Dennis (2010) Duskin (2005)	<i>M: "[The peer supporter] made it seem that her life was much better than mine."</i> (Dennis, 2010)
N6		Peers focus on sharing negative feelings and experiences, peers do not use therapeutic techniques PEERS DO NOT COMFORT EACH OTHER WHEN DISTRESSED Group does not have effective facilitation or peer supporters are not well selected/ trained	Mother responds to others' negativity or distress with own negativity and distress	Reduced emotional wellbeing, anxiety over own recovery and sadness over others' suffering	Carter et al. (2018) Pitts (1999) Prevatt et al. (2018)	M: "[The volunteer] worried that she would: Not have anything positive to say to the mother as her own experience had been so negative." (Carter, 2018) M-O: "Q: What could have helped you more? A: Always having a group discussion at the end on a happy subject, letting others input ideas/ suggestions about how other people in the group could make their lives/feelings better." (Pitts, 1999) M-O: "When they became upset, I could see they wanted to be comforted, but no-one seemed to do that. That made me very uncomfortable." (Pitts, 1999)

	Context	Negative mechanisms		Negative outcomes	Studies	Example quotations
Theory #		What happens during peer support	Reasoning or reaction of mother			
N7		Peers share unhelpful ideas about self care, coping with perinatal mental health, parenting, medication, mental health services Group does not have effective facilitation	Mother is influenced by poor advice from group members, not redressed by facilitator	Lose confidence in mental health services, use ineffective or harmful coping strategies		
N8		PEERS ARE JUDGEMENTAL OR DIRECTIVE. GROUP DOES NOT HAVE EFFECTIVE FACILITATION OR PEER SUPPORTERS ARE NOT WELL SELECTED/ TRAINED	MOTHER FEELS JUDGED AND DISEMPOWERED	REDUCED SELF- ESTEEM, DISEMPOWERMENT	Carter et al. (2018) Cust (2016) Duskin (2005)	M: "She admits she was initially judgmental of other mothers she saw who were taking care of themselves, and believed this meant they were not good mothers." (Duskin, 2005) M: "Each [peer supporter] wanted to attempt to find their own possible solution to their mother's problem." (Cust, 2016)
N9		THERE IS NOT TIME TO SPEAK OR MOTHER IS INTERRUPTED (GROUP DOES NOT HAVE EFFECTIVE FACILITATION OR THERE IS NO LIMIT ON NUMBERS)	MOTHER FEELS SHE IS NOT LISTENED TO	FRUSTRATION, NOT FEELING HEARD	Pitts (1999) Prevatt et al. (2018)	M: "Sometimes moms talked over each other, especially when groups got over 5 + people." (Prevatt, 2018)
N10	C-I12 Low social confidence	MOTHER FEELS PRESSURE TO SPEAK TO PEER SUPPORTER	PEER SUPPORT BECOMES AN ADDITIONAL STRESSFUL SOCIAL RELATIONSHIP	STRESS	Sembi (2018)	M-O: "It felt more pressured because I felt like I just kind of had to talk to [peer-supporter] though I didn't feel like I wanted to." (Sembi, 2018) M-O: "Sometimes when things were going OK if I can be honest I almost like dreaded it because I had nothing much to say." (Sembi, 2018)

#### 5.5.2 Theories N1-N2: Social failure and social loss

There was no evidence for social failure leading to reduced self-esteem, but there were some references to mothers' anxieties about not coping or losing their support network when the one-to-one or group support ended (#2,3,8). Carter et al. (2019) clarified that the mothers who expressed these fears in intervention #3 also felt that the benefits of peer support outweighed the negatives. Volunteers in intervention #2 worried about how mothers would cope when the six weeks of peer support ended, and expressed concern that they were abandoning mothers and potentially making their depression worse.

#### 5.5.3 **Theory N3: Lack of validation**

A lack of validation was reported in one in ten of the peer support relationships in intervention #6. Dennis (2010) suggested that this may have been because peer volunteers "were unwittingly minimizing participants' concerns in an effort to normalize their situations" (p. 566), due to lack of training or experience in counselling techniques. Duskin (2005) noted that all her research participants had attended the group (#7) for many weeks, and wondered whether mothers who drop out of support groups might be affected by negative social comparisons which undermine their self-esteem and worsen their depression. Some of the volunteers in intervention #3 described themselves as "feeling an overwhelming sense of naivety during their interaction with their mothers" (Carter et al., 2018 p.171), suggesting that they may also have struggled to normalise the experiences of mothers with very different lifestyles. There was no evidence of this happening in the (generally homogenous) groups.

#### 5.5.4 **Theories N4 & N5: Downward and upward social comparison**

Several studies included examples where downward social comparison had increased a mother's depression or anxiety. Most of these were from peer support groups, where mothers might become upset at hearing other mothers' stories and lose confidence in the possibility of their own recovery (#7,16,17). One mother in intervention #3 had asked to change her one-to-one peer supporter because she was distressed about the peer supporter's oversharing of her own serious mental health experience.

There were only two references to negative upward social comparison. One mother in intervention #7 initially felt threatened by the success of another mother in the group, before becoming inspired by her, and a mother in intervention #6 felt *"put down"* by her volunteer (Dennis 2010).

#### 5.5.5 Theory N6 & N7: Unhelpful advice or negativity

It was hypothesised that if groups were not adequately facilitated, a depressogenic culture of negativity might develop, or peers might share misleading or otherwise unhelpful advice, leading mothers to use

ineffective or harmful coping strategies or to lose confidence in mental health services. There was no evidence of the latter, but brief allusions to the former both in groups (#16) and one-to-one (#3). One mother in intervention #16 found it upsetting that others at the group did not respond empathetically by comforting a group member who was distressed. Many mothers in intervention #8 felt worse during the first seven group sessions, which were focused on disclosure of feelings, but this was understood as a necessary stage. This may be considered a contradiction to theory 14, where mothers felt a liberating relief at expressing their feelings for the first time. There were no specific contextual factors identified that would make these mechanisms more or less likely.

### 5.5.6 **Theories N8-N9: Peers are judgemental or directive, mother not heard**

There were also some unanticipated negative theories. Being a mental health peer was not *necessarily* a guarantee of an initial non-judgemental attitude to other mothers (#3,7). Volunteers with limited training did not *necessarily* know how to give help without giving directive advice, particular if they believed they were going to solve a mother's problems (#2,3). There were also indications that some mothers felt a group of more than six was too big, because mothers talked over each other and lengthy introductions left little time for discussion (#16,17), but it was not clear whether this was something that simply made the peer support less effective, or actively undermined emotional wellbeing by making mothers feel that - once again - they could not make their voices heard.

#### 5.5.7 Theory N10: Peer support as a stressful social relationship

In intervention #6, almost half of peer volunteers said they had been disappointed, usually because the mother did not need support or did not return their calls: these mothers appeared to successfully control their contact with their peer supporter. By contrast, two mothers in intervention #18 did not feel able to refuse a booked peer support telephone conversation. This suggests that the mothers lacked either the social confidence or the trust with their peer supporter to tell her honestly that they did not want to speak to her that day, and in these cases the peer support relationship became an additional source of social stress.

# 5.6 Discussion

This review has explored how different contextual factors may trigger mechanisms that lead to a mother taking up an offer of peer support. It has also highlighted the complexity of peer support interactions, and the range of contexts and both positive and negative mechanisms that may interact to produce a

variety of proximate outcomes for an individual mother with perinatal mental health difficulties, as well as a measurable short-term improvement in depressive symptomology.

The realist approach helps to explain why peer support appeals to some mothers but not others, and 'works' for some mothers but not others. Mothers with perinatal mental health difficulties are heterogeneous in their backgrounds, personalities, social situations, resources, and needs. Community-based peer support programmes are also heterogeneous in the format of what they offer and their criteria for who can make use of their support. By seeking out the differences as well as the commonalities, this review has generated a more complex picture of perinatal mental health peer support than portrayed in previous qualitative syntheses. For example, Jones et al. (2014a) focused on peer support as a way to 'unsilence' the 'silenced voice' in the context of unrealistic expectations or beliefs about idealised motherhood, consistent with theories 14 (feeling understood), 15 (feeling accepted) and 17 (normalisation), but did not identify the important contribution of mothers sharing their ideas about self-care, coping with perinatal mental health and parenting challenges (theory 18). These could be of independent value to a mother even if she was emotionally well-supported by others in her social network.

There was no evidence from the interventions in this review suggesting that the mechanisms worked differently for first time mothers compared to mothers who already had a child, for mothers with a history of mental health difficulties compared to mothers with no previous history, or for mothers with a partner compared to single mothers. There was also no evidence that there was any specific 'dose' of peer support that was more or less effective than any other, nor that any particular mental health scale cut-off for the lower or upper boundary of access to the peer support affected its effectiveness. It was suggested by Shorey and Ng (2019) that peer support might be particularly useful for mothers in conservative Asian cultures, but the evidence in this review was that mothers in other cultural contexts (the UK, USA and Canada) also found it difficult to talk to their social network about their mental health difficulties, and the mechanisms related to non-judgmental empathetic listening appeared to be cross-cultural.

There was some evidence that shared experience of perinatal mental health difficulties alone might not always be a sufficient basis for some peer support mechanisms, particularly empathy and the formation of social relationships. One-to-one peer support relationships could be strengthened by careful matching based on similarities in background and interests. There was not enough detail to draw clear conclusions about the extent to which mothers valued social or cultural similarity within a peer support

group. Although the majority of participants in most studies tended to be socio-economically advantaged and educated, there were also examples of interventions that had successfully devised ways to overcome structural barriers to access that might affect more disadvantaged mothers.

The different formats of peer support had the potential to engage and benefit mothers in different ways. One-to-one telephone support offered the possibility of a convenient, flexible, anonymous peer support relationship that did not incur travel costs or time, and thus might improve access for disadvantaged mothers. There were, however, limitations on the strength of relationships that could be formed by telephone, and support by telephone may have had a weaker effect on loneliness. One-to-one face-to-face support had the potential for stronger relationships and more in-depth disclosure, but would not suit mothers who valued anonymity, and might have travel implications for the mother if meetings were not at her home. One-to-one support in general might have social costs for mothers who did not have the confidence to break appointments that they did not want to keep, and could have some risks if the peer supporter was insufficiently trained in how to have supportive conversations.

Group support offered a wider range of peer experiences with greater potential for social comparison, sharing coping strategies and the opportunity for reciprocal support, although there was unexpectedly little evidence reported of mothers benefiting through the opportunity to help others. Group support might create the opportunity for new friendships, particularly benefiting mothers who were socially isolated. It offered some mothers a structure, a reason to leave their home, and a break from their children, although it also involved travel costs and time. Group support that was offered on a drop-in basis might be more accessible to busy mothers who could not commit to a specific number of weeks (theory 10), but equally a drop-in format might undermine the social relationships that could form if the same mothers attended regularly (theory 22).

Group support was not suitable for mothers who lacked the social confidence to attempt a group situation, and if it was not well facilitated had risks of several negative mechanisms. None of the included interventions offered mothers a choice of one-to-one or group support, so there was no evidence about how these might compare in practice for individuals. In 2020, due to the coronavirus pandemic restrictions on meeting, most face-to-face perinatal peer support in England was replaced by videoconferencing (Parents 1st, 2020), but this change was outside the scope of this review.

There was a clear overlap between the theories identified for group peer support and the social psychological mechanisms active in group psychotherapy (Scope et al., 2012; Yalom & Leszcz, 2005), as

discussed in Chapter 4. Prevatt et al. (2018) noted that the same was true for negative mechanisms (#17). There was also a substantial overlap between the mechanisms related to the use of volunteers to deliver one-to-one mental health peer support in these interventions, and those found in other forms of one-to-one volunteering in the perinatal period (McLeish et al., 2016a; McLeish & Redshaw, 2015). Difficulties in balancing numbers of volunteers and numbers of mothers referred for support are common in the early months of volunteer-based programmes (McLeish et al., 2016b), but these were only reported in intervention 18, where there was a six month gap between the volunteer training and recruitment of the first mother, during which time a third of the volunteers left the programme. There was an unresolved tension between the desire in some interventions to train peer supporters as little as possible (e.g. #2,3,6) to avoid 'professionalising' their role or overtaxing the volunteers, and the benefits of a more comprehensive training in active listening and support skills (McLeish et al., 2016a). All the training in the included interventions was much shorter than in other perinatal one-to-one volunteer support interventions in England (McLeish & Redshaw, 2015), although it was notable that there was a trend for training to be lengthened when models were replicated (#3,12,18). This relative lack of training may have contributed to some negative theories when volunteers gave directive advice in the belief that their role was to 'fix' or 'solve' the mother's problems for her (theory N8), failed to validate mothers' problems (theory N3), and overshared their own experiences (theory N6).

Most of the theories that appeared in the final theoretical model had been hypothesised in the initial model, but there were some entirely new C-M-O configurations identified from the empirical studies and there were also new individual contexts and mechanisms added to some theories. There was no evidence for two of the negative hypothesised theories (N1 – mothers' attempts at friendship fail; and N7 – mothers share unhelpful information).

Although there was evidence for a range of psychological benefits from peer support, it was not possible to integrate these fully with the evidence about the impact of peer support on measurable depression and anxiety outcomes as assessed by validated screening questionnaires. There was RCT evidence for statistically significant short-term improvements in depressive symptomology for both group and one-to-one peer support, but not for anxiety. There was no evidence in this review to connect these improvements to any individual C-M-O configuration more than any other. The detachment of these 'hard' mental health outcomes from the proximate outcomes reported through qualitative evidence and non-screening questionnaires mirrors the complexity of the concept of 'recovery' in mental health (Davidson & Roe, 2007; Leamy et al., 2011). It is plausible that, through the activation of one or more of

the C-M-Os, peer support has a direct impact on recovery from the symptoms of perinatal mental health difficulties as measured by mental health scores. However, it might be also possible for a mother to have improved her subjective wellbeing - through reduced feelings of guilt, shame and alienation, and increased ability to cope with parenting and her mental health difficulties – while remaining depressed or anxious as measured by a screening questionnaire; this could be considered recovery 'within' mental health difficulties.

This latter view is consistent with Rosenberg (1984)'s analysis of support groups as offering "comfort rather than cure" (p.178). It was, however, clear from the use of mental health scales by many of the interventions in this review that community-based peer support programmes may seek to demonstrate that they can also offer a form of 'cure'. This may be influenced by the requirements of funders as well as a desire to show mothers and potential referrers that the peer support is effective. These two different versions of 'outcomes' reflect the paradox inherent in the 'normalisation' of perinatal mental health difficulties through peer support, as noted by Taylor (2000). Mothers seek out and benefit from lateral social comparison which 'normalises' their current difficult emotions, but at the same time seek out and benefit from upward social comparison in the hopeful stories of mothers who have recovered and returned to a more mainstream 'normality' where they no longer have those difficult emotions.

# 5.7 Strengths and limitations of the realist review

The process of realist review was challenging in its relatively unstructured nature. In particular, the lack of defined boundaries for the stage of exploratory searching meant that there was a strong pragmatic element in deciding when to stop. There was also an element of artificiality in excluding familiar empirical papers about perinatal mental health peer support when constructing the initial theoretical model. At the stage of searching for empirical studies, it was not always straightforward to determine whether what was reported as a 'peer support' group might in fact be a form of 'therapy' group. The decision to include any intervention that described itself as a perinatal peer support group, and was not facilitated by a mental health professional, may have led to the inclusion of groups that could have felt like basic therapy groups to participants. On the other hand, from the perspective of an individual mother, the distinction between a 'therapy' group with peers and 'peer support' where mothers share therapeutic techniques might in any case be unclear. It was disappointing that responses were received from only three of the 11 community programmes contacted, as these added insights drawn from ongoing peer support interventions, whereas most of the peer-reviewed studies identified through database searches were of interventions that only existed for the period studied. They also illustrated how in community settings, peer support could be integrated as part of a broader offering of support for perinatal mental health difficulties from the same organisation, with the potential to overcome some of the contextual barriers to accessing 'pure' peer support. It was a strength that the review was informed by discussions and debate with providers and commissioners of community-based peer support at multiple events during the different stages of the review.

The overall quality of included studies was extremely variable, with some methodologically high quality and others very low quality. However, this review was strengthened by the inclusive realist approach of examining every source critically for the trustworthy pieces of information it could yield. Even where a study's findings were not reliable due to methodological flaws, relevant and reliable evidence could be extracted about how the peer support was offered. The synthesis of information from heterogeneous sources enabled the construction and testing of a detailed theoretical model of perinatal mental health peer support that illustrates the complexity of positive and negative peer support mechanisms and the contexts in which they may be triggered for different women.

The exercise of searching for C-M-O configurations in the included studies illustrated the challenge of looking through a realist lens at non-realist evidence. Non-realist authors do not necessarily investigate or report aspects of their programme that a realist would see as contextual factors or mechanisms, and journal word limits and reporting conventions can restrict detailed description of the intervention: lack of evidence for programme theories could be an artefact of limited reporting or limited insight (Pawson et al., 2005). It was rare for evidence of a full C-M-O configuration to appear in an individual paper. On the section A topic of mothers choosing to take up peer support, there was abundant evidence for potential contexts but the mechanisms were not usually explicit. On the section B and C topics of how peer support may work positively or negatively, there was abundant evidence for mechanisms and some for proximate outcomes (aspects of mothers' self-reported psychological wellbeing or actions) but little on contexts, and it was not possible to link measurable mental health outcomes to specific C-M-Os. The theoretical model as presented therefore retains a level of hypothesis and scope for future exploration of full C-M-O linkages.

# 5.8 Chapter summary

The search for empirical studies identified 29 sources describing 22 perinatal mental health group and one-to-one peer support interventions. These used a range of methodologies and were of varied methodological quality, but there were reliable and relevant pieces of information in all of them. The final theoretical model was created by testing the initial theoretical model against the C-M-O analysis of this empirical evidence. This model included 13 programme theories explaining take-up of peer support, 11 programme theories explaining how peer support can work positively, and eight programme theories explaining how it can work negatively.

The next chapter describes the methods used in the primary research study of Parents in Mind.

# 6 Parents in Mind Study - Methods

# **Chapter overview**

This chapter sets out the methods used for the primary research study of the Parents in Mind pilot. It explains how an initial theory of change was developed to guide the evaluation. It describes the data sources chosen to answer the evaluation questions; the participants; the data collection measures, methods and procedures; and the data analysis, leading to the creation of a final theory of change.

# 6.1 Design

This was a mixed methods, critical realist, theory-based process evaluation of the Parents in Mind pilot.

# 6.2 Research questions

Following discussion with the programme developers, the following priority questions were formulated:

- 1. What was implemented in Parents in Mind?
  - a. How was Parents in Mind staffed?
  - b. How many volunteers took part, what were their socio-demographic characteristics, and how were they recruited, trained and supported?
  - c. How many mothers were referred and by whom, what were their socio-demographic characteristics, how many took up peer support and how much peer support did they receive?
  - d. What adaptations were made at the three sites and why?
- 2. What are the mechanisms that affect take-up of Parents in Mind peer support in different contexts?
- 3. What are the positive and negative mechanisms of change within Parents in Mind peer support, what are the contextual factors that trigger those mechanisms and what outcomes do they produce, for supported mothers?
- 4. What are the positive and negative mechanisms of change within Parents and Mind, what are the contextual factors that trigger those mechanisms and what outcomes do they produce, for volunteer peer supporters?
- 5. How do the mechanisms of peer support differ in different models of peer support (within a volunteer-led group or one-to-one)?
- 6. What is needed to support the emotional wellbeing of volunteer peer supporters?

# 6.3 Setting

Parents in Mind is a third sector perinatal mental health peer support programme, run by national charity NCT. A full description of the programme is given in Chapter 7. Parents in Mind is an ongoing programme, but this chapter uses the past tense because this study was based on the pilot phase (2016-19), funded by the Department of Health's Innovation, Excellence and Strategic Development Fund. The pilot ran at three sites in Coventry and Warwickshire, Widnes and Runcorn, and the London Borough of Newham<sup>2</sup>. The programme has subsequently evolved and expanded.

# 6.4 Ethical approval

Ethical approval was granted on 23 December 2016 by the Research Ethics Committee of the School of Health Sciences, City, University of London (Ref: PhD/16-17/08) (see Appendix E).

# 6.5 Defining project relationships

The Medical Research Council recommended that the first step in an evaluation should be to define the parameters of relationships with intervention developers, balancing the need for good working relationships against the need for independence to maintain credibility (Moore et al., 2015). This was particularly pertinent for this evaluation, because the researcher and two of the academic supervisors were already members of a project advisory group convened to support the development of Parents in Mind, before becoming its evaluators. Although this was not a steering group and did not have any decision-making powers, it was important to clarify roles when potentially attending this group both as advisers and as evaluators.

It was therefore agreed with programme staff that evaluation team members would attend project advisory meetings both to support the programme and to support the evaluation, by:

- Contributing knowledge and expertise in the field
- Building and maintaining relationships with staff
- Learning about the programme's processes and decision-making

<sup>&</sup>lt;sup>2</sup> The sites are identified here, because they have already been publicly identified in the project report (McLeish & Hann, 2020) and on the NCT's website https://www.nct.org.uk/about-us/community-support-programmes/parents-mind-perinatal-mental-health-peer-support

• Informing staff and the advisory group about the progress of the evaluation.

It was agreed that notes of discussions at project meetings could form part of the evaluation.

### 6.6 Developing the initial theory of change

The first step in a theory-based evaluation is articulation of the initial theory of change, which is tested during the evaluation (Coryn et al., 2011). The programme developers initially created a basic logic model describing the anticipated inputs, activities and outcomes. They had not identified the potential mechanisms of change nor considered potential adverse mechanisms and outcomes – they had an implementation theory (action model) but not a programme theory (change model) (Chen, 2005; Weiss, 1995).

As recommended by Patton (2010), an initial theory of change was formulated by combining programme stakeholders' own theories (logic-in-use) of how the programme worked with other evidence. When the Parents in Mind pilot began, the stakeholders were staff and the project advisory group. Their implicit theories of how peer support might affect perinatal mental wellbeing were explored during project meetings, and programme documents were reviewed to identify the claims being made about mechanisms and outcomes. More detailed theoretical pathways were derived from the literature used for the realist review's initial theoretical model (Chapter 4).

From these sources, potential mechanisms were hypothesised by which Parents in Mind peer support might positively affect outcomes for mothers and volunteers in different contexts, and also potential negative mechanisms and outcomes. Mechanisms relating to take-up of Parents in Mind peer support were also hypothesised. Following stakeholder discussion, these were incorporated into an initial theory of change for Parents in Mind. The hypotheses of this theory of change were tested and refined in the course of the research.

# 6.7 Data sources

Data collection drew on the following sources:

#### Data collected by the researcher:

1. Semi-structured interviews.

2. Notes of meetings with staff and the project advisory group.

# Data routinely collected by staff and shared with the researcher:

- 3. Demographic data about all mothers referred to the programme (anonymised).
- 4. Demographic data about volunteers collected before training (anonymised).
- Data about supported mothers' use of the programme, recorded by local project managers (anonymised).
- 6. Data about volunteers' participation in the programme, recorded by local project managers (anonymised).
- 7. A mental health questionnaire completed by supported mothers at the referral meeting and approximately every two months during their support.
- 8. An additional questionnaire about peer support, completed by supported mothers at the referral meeting and approximately every two months during their support.

# Other data made available to the researcher by staff

9. Programme papers (for example, funding applications and reports)

Data were collected between September 2016 and June 2019, covering an additional three months following the end of the pilot in March 2019. Table 8 shows the research questions for which these data sources were used.

It was intended that two further data sources would be used: an activity log completed by volunteers that would enable tracking of the amount and type of peer support given to individual mothers, and a reflective session log recording the reflective support sessions for volunteers. However, both of these were filled out too inconsistently to provide any useful data.

# Table 8 Data sources for the research questions

	Research question	Data sources
1.	What was implemented?	Demographic and programme use data
		Mental health questionnaires
		Interviews – staff, trainers
		Notes of project meetings
2.	Contexts and mechanisms related to the	Interviews – mothers, volunteers, staff
	outcome of participation	Mothers' additional questionnaires
3	Positive and negative peer support C-M-	Interviews – mothers, volunteers, staff, trainers
	O configurations for supported mothers	Mental health questionnaires
		Mothers' additional questionnaires
4.	Positive and negative peer support C-M-	Interviews – mothers, volunteers, staff, trainers
	O configurations for volunteers	
5.	Mechanisms in different models of peer	Interviews – mothers, volunteers, staff
	support	
6.	Supporting emotional wellbeing of	Interviews – volunteers, staff
	volunteer peer supporters	

# 6.8 Participants

Participants were purposively recruited for their knowledge and experience of Parents in Mind from four groups:

- 1. Mothers women who had received or were still receiving support from Parents in Mind.
- 2. Volunteers women who enrolled on the Parents in Mind training, in order to become a peer supporter.
- 3. Staff those employed locally at each site or involved in national project management.
- 4. Trainers who trained the Parents in Mind volunteers.

An overview of the timing of data collection from each group of participants is shown in Figure 5.

# Figure 5 Overview of data collection



# 6.9 Data collection - quantitative

# 6.9.1 **Consent process**

When a woman was referred (or self-referred) to Parents in Mind, the local project manager met her and explained what the programme could offer. The local project manager obtained her written informed consent to share data from her questionnaires with the researcher.

### 6.9.2 **Choice and development of data collection instruments for mothers**

Data collection instruments were chosen or co-designed by the evaluation team and programme staff, to ensure that they would workable in practice while meeting the twin goals of (1) enabling an initial assessment and subsequent reviews of mothers' emotional wellbeing, and (2) also yielding data for the evaluation.

### 6.9.3 Mental health self-report questionnaire

### 6.9.3.1 Staff requirements for a questionnaire

A validated self-report questionnaire was used to track changes in mothers' emotional wellbeing during the time they were using Parents in Mind. Staff had three main requirements in the choice of the questionnaire:

- (1) The scale must be suitable to be filled in by the local project manager during discussion with the mother, initially face-to-face and subsequently by telephone, and must therefore be relatively short (<20 items).</p>
- (2) Baseline scores must help the local project manager to make a decision about whether Parents in Mind would be suitable and safe for the mother, but specific cut offs were not defined.
- (3) Follow-up scores must enable the local project manager to track a mother's progress and potentially to reach a decision, in partnership with the mother, that Parents in Mind support was no longer needed or appropriate.

# 6.9.3.2 Choosing the Hospital Anxiety and Depression Scale

A variety of validated self-reported questionnaires were considered, measuring constructs related to hypothesised mechanisms and outcomes in the theory of change, including depression, anxiety, social support, self-esteem, parenting confidence, and stigma. Following discussion with staff, the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was chosen. HADS consists of two subscales, Anxiety (HADS-A) and Depression (HADS-D). Each subscale has seven questions with four answer options that are scored 0-3. The scores for each subscale are to be considered separately.

Zigmond and Snaith defined a score of 0-7 as indicating the 'normal' range, 8-10 indicating 'mild' disorder, 11-14 'moderate' disorder, and 15-21 'severe' disorder (Snaith & Zigmond, 1994). A review of studies concerned with the validity of HADS in non-perinatal populations confirmed that an optimal balance between sensitivity and specificity was achieved when caseness was defined by a score of 8 or above on each subscale (Bjelland et al., 2002), and a study of pregnant women using this cut-off found very high sensitivity (93% for anxiety, 90% for depression) and specificity (90% for anxiety and 91% for depression) (Abiodun, 1994). The review by Bjelland et al. (2002) assessed HADS as a reliable self-report instrument because Cronbach's coefficient alpha for HADS-A was .68 to.93 (mean.83) and .67 to.90 (mean.82) for HADS-D.

There were reservations about the choice of HADS. There is contradictory evidence about its factor structure in diverse pregnant populations from the UK (Jomeen & Martin, 2004; Karimova & Martin, 2003), Uzbekistan (Karimova & Martin, 2003), Pakistan (Lodhi et al., 2020; Waqas et al., 2019) and Japan (Ogawa et al., 2021). It has not been validated for postnatal populations, and some of the anxiety items have been critiqued as potentially having a different meaning for perinatal populations, for example, 'I can sit at ease and feel relaxed' (Meades & Ayers, 2011).

It was nonetheless felt to be the best instrument for self-assessment of symptoms in the *non-clinical* setting of Parents in Mind, using each subscale independently as intended by its originators, for five reasons:

- It addresses symptoms of both depression and anxiety, which are the most common affective difficulties experienced in the perinatal period.
- (2) It includes positive as well as negative statements, e.g. 'I can laugh and see the funny side of things'. This was more consistent with the strengths-based approach of peer support than the entirely negative statements of the Edinburgh Postnatal Depression Scale (EPDS), (Cox et al., 1987), Patient Health Questionnaire 9 (PHQ-9) (Spitzer et al., 1999), or Generalized Anxiety Disorder 7 item scale (GAD-7) (Spitzer et al., 2006), which are the screening tools recommended for perinatal anxiety or depression *in clinical practice* (National Institute for Health and Care Excellence, 2014).
- (3) It excludes somatic symptoms such as tiredness or sleep difficulties (Zigmond & Snaith, 1983), which could be misleading in a perinatal population, and therefore has been used in other perinatal research (Barlow & Coe, 2012; Lee et al., 2007).

- (4) The less clinical tone was more appropriate for a telephone conversation than PHQ-9, GAD-7 and EPDS.
- (5) A questionnaire with 14 questions about mood, each with four possible answers, was feasible by telephone. The use of multiple scales was rejected to reduce participant burden.

# 6.9.4 Additional questions for mothers

To investigate hypothesised outcomes and mechanisms on the theory of change, additional questionnaire items were developed. These were in four groups:

- (1) Issues expected to be affected by peer support (e.g. '*There is someone I can talk to who understands me'*), with four response options from 'not at all' to 'a lot'.
- (2) The participant's attribution of change (e.g. '*Parents of Mind has helped me to find ways of coping when I'm feeling down'*), with four response options from 'not at all' to 'a lot'.
- (3) Alternative causal explanations (e.g. 'Are you taking any medication for your mental health at the moment?') with binary response options (yes/no) and a follow-up from 'yes' (e.g. 'If yes: do you feel it is helping you feel better?) with binary response options (yes/no).
- (4) Open text questions about what the mother hoped to get out of Parents in Mind (at baseline only), her goals, what she felt she had got out of the support, and (if applicable) why she had stopped attending.

Questionnaires are in Appendices C and D.

# 6.9.5 **Procedure for routinely collected data**

# 6.9.5.1 Demographic data and service use

Mothers were referred or self-referred to Parents in Mind using a referral form that asked for demographic information, the reasons for the referral, details of any previous mental health history, and any other agencies which the mother was currently accessing.

Each local project manager maintained two basic logs in the form of Excel spreadsheets. The first was used to record data on the mothers referred and receiving support. The second was used to record data on the numbers, demographics and motivations of volunteers starting and completing training, volunteering, and leaving.

These data were shared with the researcher as anonymised programme data.

#### 6.9.5.2 *Questionnaires*

The local project manager completed the HADS and additional questionnaire as part of a conversation with the mother during an initial visit. Mothers were invited to complete follow-up questionnaires every two months (initially by telephone, and later with the option to complete an online version).

#### 6.10 Data collection - qualitative

Participants were purposively (theoretically) sampled for the relevance of their experiences and insights into the developing programme theories. They either had experience of giving or receiving peer support as part of Parents in Mind, or had knowledge of the programme through their roles in management or training.

### 6.10.1 Interviews: mothers and volunteers

Semi-structured, in-depth interviews were chosen as the qualitative data collection method for mothers and volunteers because of the sensitive nature of the topic and the desire to probe contextualised individual experiences and understandings (Braun & Clarke, 2013). Mothers and volunteers each took part in a single research interview. Interviews were spread out across the pilot to capture experiences at different points in the programme's development, and also to enable theory building by checking theoretical insights developed through earlier interviews (Manzano, 2016).

It has been suggested that it may be more difficult to build rapport by telephone than face-to-face, and non-visual responses and symptoms of distress could be missed (Miller, 1995); on the other hand, some interviewees prefer the telephone because it is more convenient and anonymous (Fenig et al., 1993). It has been shown to be possible to achieve similar content and depth using either type of interview, if the interviewer attends carefully to verbal cues (Sturges & Hanrahan, 2004). Supported mothers and volunteers were therefore offered the choice of being interviewed face-to-face during the day at a place of their choice (including their home or a community location), or by telephone at any time including evenings and weekends.

#### 6.10.2 Interviews: staff and trainers

Semi-structured interviews were also used for staff and trainers, to enable in-depth discussion of their experiences at individual sites. Cross-site issues were discussed at project meetings, so a focus group to explore similarities and differences was unnecessary.

Local and national project managers were interviewed every six months. The purpose of this longitudinal design with key informants was to understand how Parents in Mind was adapted during the pilot, and how local contextual factors affected it at different time points. From the realist perspective, it was also to enable the different phases of realist interviewing to take place with those who were expected to be most knowledgeable about the workings of the programme: theory gleaning, theory refining and theory consolidation (Manzano, 2016). Project managers were initially interviewed face-toface to facilitate relationship-building, and for subsequent interviews were offered the choice of an interview by telephone or face-to-face.

The trainers and peer support team leader were each interviewed once by telephone, near the end of the pilot. For the peer support team leader, this was because her role was created during the pilot's final year. When it became apparent that volunteers' experiences as peer supporters had been affected by the specific training they had received at the different sites and in particular the confused messaging about talking about lived experience (see section 7.5.10), it was decided to interview the trainers to understand their perspectives on this issue and the ways in which the training had evolved.

#### 6.10.3 Recruitment and consent

Participants were invited to take part in interviews in one of two ways:

- (1) Staff and trainers were invited by the researcher.
- (2) Supported mothers and volunteers were invited by their local project manager. If they were interested, the project manager passed their contact details onto the researcher, who arranged an interview.

Mothers were ideally invited at the end of their peer support, or when they had experienced at least three months of support. Volunteers were invited when they had at least six months' experience of giving support, or when they had left the programme.

All potential participants were emailed a participant information leaflet and consent form at least 48 hours before the interview (see Appendix F for the leaflets and the consent forms for mothers – the wording was adapted for volunteers and staff). Before an interview began, the researcher reiterated the purpose of the research, the principle of confidentiality and the right of the participant to pause or stop at any time, and invited questions about the research. For the local and national project managers, the principles of voluntary participation and confidentiality were slightly different, as transparent

participation in the evaluation was an expected part of their employment. Confidentiality was managed by inviting them to indicate any parts of the interview that were 'off the record'.

If a participant chose to be interviewed face-to-face, her written informed consent was obtained before the interview began; if by telephone, her informed consent was obtained orally and recorded in writing.

# 6.10.4 Topic guides and question types

Interview topic guides were developed using the initial theory of change. They reflected the stage of the programme and the role of the interviewee within Parents in Mind, and explored the interviewee's experiences and views with an underlying focus on possible contextual factors, mechanisms and intended and unintended outcomes. Examples of first-interview topic guides, which were used flexibly, are in Appendix G. During the interview, a variety of question types were used to explore the interviewee's experiences and views, as recommended by Kvale (1996). Box 2 shows some examples of questions used in practice.

Sections of interviews were carried out using an explicitly realist approach, where appropriate. This involved the researcher describing ('teaching' the interviewee) the developing theory of change and the interviewee therefore being able to respond ('teaching' the interviewer) with their perspective on it, enabling further clarification and elucidation of conceptual ideas (Pawson, 1996). To minimise the risk of confirmation bias, realist interviewing was only used after the interviewee had first been invited to share their own ideas and experiences. At first the theories discussed were constructs from the initial theory of change, and as revised theories were developed, these were shared with staff informants in later interviews.

# Box 2 Examples of different types of questions used to explore experiences and views

Type of question*	Example from interviews
Open introducing questions	"Could you tell me about the mental health issue that led you to use Parents in Mind?"
Follow- up questions that encourage the interviewee to elaborate on a topic	<i>"What was the role of the volunteers in that group?"</i>
Probing questions, pursing aspects of answers for more detail	"The phrase you used for that medication, about letting your mind clear - could you say more about how that's helped?"
Specifying questions that ask for particulars	"Compared to that previous depression, did this experience that you've had after your baby was born feel like it was the same thing?"
Interpreting questions, that rephrase what has been said for clarification or interpretation	<i>"So one thing is feeling bad, and then there's being made to feel bad about feeling bad?"</i>
Silence, that encourages the interviewee to reflect and break the silence themselves.	
*As recommended by Kvale (1996).	

Some questions focused specifically on exploring potential contextual factors, positive or negative mechanisms, and intended or unintended outcomes.

C-M-O questions	Example from interviews
Question about context	"Do you think this is a wider cultural problem, that people are just not sharing what pregnancy and parenthood are like in an honest way?"
Question about positive mechanism-outcome	"In terms of the impact on you, does getting those things off your chest make a difference to how you were feeling?"
Question about negative mechanism-outcome	"When you think about peer support in general, do you think there are any downsides or any times when it might actually have a negative impact on somebody?"

#### 6.10.5 Sample size for interviews

Estimating sample size in advance of beginning qualitative research is inherently difficult and the estimate may be particularly weak in realist qualitative research where the interviewer will need to pursue theoretical leads (Emmel, 2013). As this was a small programme, it was feasible to interview all the staff and trainers. The estimated sample size was 8-12 mothers and 8-12 volunteers at each of the three sites (based on previous experience of research in perinatal volunteer programmes), but recruitment at a site would be stopped earlier if thematic saturation was reached with fewer interviews – that is, interviewees were repeating similar information and there were no new codes or themes identified (Saunders et al., 2018). It would have been preferable to use the Grounded Theory test of theoretical saturation, where no additional data are found that can develop properties of the theoretical category (Glaser & Strauss, 1967), as this would be more appropriate for the critical realist enquiry (Maxwell, 2012). However, the sequencing of the research process did not make this possible. Initial open coding and focused coding (Corbin & Strauss, 2015) were carried out iteratively with data collection. Full theoretical coding was carried out following completion of the realist review, after interviews had ended.

#### 6.10.6 Truth in the realist interview

Critical realists accept that interviews are co-constructed by interviewer and interviewee, but not that they are *only* constructions unrelated to an independent reality. Interview data (like other data) are seen as "evidence for *real* phenomena and processes (including mental phenomena and processes) that are not available for direct observation" (Maxwell, 2012, p. 103), and thus a crucial part of the realist attempt to understand causal mechanisms. Nonetheless it was important to consider the relationship between what was said in an interview and its representation of truth, which could be affected by issues such as fallible memory recall, reliance on a "cultural stock of stories" (Polkinghorne, 1991), or social desirability. The strategies suggested by Westhorp (2008) were used to compensate for these possibilities and inform the researcher's judgement about the truth of any claim in a realist context, including: tracking the internal logic of claims and patterns between different respondents; checking for inconsistencies within an interview or between multiple interviews with the same respondent; assessing consistencies with theory.

#### 6.10.7 **Reflexivity as an interviewer**

As most of the interviews with mothers and volunteers were carried out by telephone, the interviewee's initial impression of me as interviewer would be based on my name, accent, and our introduction

through the Parents in Mind local project manager. I sought to build rapport by ensuring that the tone of each interview was empathetic, respectful and affirming (Kvale, 1996). Interviewees were from a range of geographical and educational backgrounds and I was conscious of the need to find the appropriate language register for each individual, including adopting their terminology if this would make it easier for us to understand each other. I was also mindful of the potential power dynamics within the interview. In order to give the interviewee as much control as possible, I adopted a style of semi-structured interviewing which is primarily structured around the interviewee's responses, follows their interests, and accommodates lengthy digressions. The topic guide was not used to interrupt the sequence of their thoughts, but as a mental checklist to ensure that all relevant topics had been explored by the end of the interview.

Interviews with staff raised different issues. Maxwell (2012) notes that for the critical realist, research relationships are real phenomena and are indeed part of the actual methods of the research. I had longstanding warm professional relationships with the interviewees who had national programme management responsibilities, which made it possible to have frank conversations from the outset. I had no previous relationships with any of the other participants, but built up relationships with the local project managers during the course of repeated interviews and feedback. These interviews became progressively longer as they developed into conversations that blended semi-structured interviewing, information-sharing, comparison with other sites, theoretical discussion, reflection and support: *"You should include in your report that the local project managers see you as our clinical support and look forward to safely debriefing!"* (LPM, site 3)

#### 6.10.8 Memos

Reflective memos were written after each interview, to capture thoughts about theoretical leads and the interview process.

#### 6.10.9 Researcher's notes of meetings

The researcher took hand-written notes at project meetings throughout the pilot, including sessions to share emerging findings from the evaluation with Parents in Mind and NCT staff. These discussions were sources of information about process challenges, solutions and adaptations.
# 6.11 Data management and confidentiality

### 6.11.1 Programme data

The programme logs on mothers' and volunteers' participation were maintained in the form of password protected Excel spreadsheets. Each mother was allocated a reference number by the local project manager that included site initials – CW for Coventry and Warwickshire, WR for Widness and Runcorn, N for London Borough of Newham. This reference number was used when recording information about the mother.

### 6.11.2 Questionnaire data

After a questionnaire was completed by a mother, the local project manager transferred the data to a password protected Excel spreadsheet, and removed data pertaining to mothers who had not consented to take part in the research before sharing it.

### 6.11.3 Interviews

All interviews were audio-recorded. Mothers' and volunteers' interviews were fully professionally transcribed. The researcher transcribed the audio-recordings of interviews with staff and trainers, verbatim for parts relevant to the research, and in note form for other parts.

To protect the anonymity of mothers and volunteers who took part in interviews, they were each given a pseudonym, which is used when quoting them. Personally identifying data were removed from transcripts. Anonymisation of data from most programme staff was not possible (given the small numbers) or desirable (given the importance of exploring their views on the specific contexts of the three different sites). Any part of an interview that the staff member indicated was 'off the record' was not transcribed.

### 6.12 Data analysis

### 6.12.1 Quantitative data analysis

Quantitative data were imported from the Excel spreadsheets into SPSS software. Data analysis was primarily descriptive, consistent with the limited purposes for which these data were used.

### 6.12.1.1 Programme data

Descriptive statistics were used to analyse programme data about demographics, take-up and use of peer support by mothers; and about numbers and demographics of volunteers, their motivation and retention. All these data were categorical and analysed as percentages.

### 6.12.1.2 HADS scores from mothers' questionnaires

Mothers' HADS scores were analysed using descriptive and inferential statistics:

(1) The median, range and interquartile range for mothers' scores for anxiety and depression were calculated at baseline, for research question 1. The Kolmogorov-Smirnov test of normality indicated that neither anxiety scores (p=0.007) nor depression scores (p=0.005) were normally distributed, so median values and range were used. Interquartile range was used because the skewness of the data made the standard deviation less appropriate.

(2) Changes in mothers' HADS scores between baseline and their final assessment were analysed for research question 3 as repeated measures using the non-parametric related samples Wilcoxon signed rank test, because the Kolmogorov-Smirnov test of normality indicated that changes in anxiety scores were not normally distributed (p=0.000). For consistency, the same test was used for the change in both anxiety and depression scores.

Changes in these scores were not relied on in this research as straightforward evidence of the impact of peer support on mothers' depression and anxiety, since an observational before/after design cannot demonstrate causation in the absence of a control group. Instead they were integrated into the critical realist analysis of how the mechanisms of peer support may produce a range of outcomes in a range of contexts.

#### 6.12.1.3 Additional questions from mothers' questionnaires

Data about answers to additional questions related to mood, and attributions of impact, were categorical and analysed as percentages.

### 6.12.2 Qualitative data analysis

Qualitative data analysis was grounded in a critical realist perspective on social reality as stratified (Bhaskar, 2008; Pawson & Tilley, 1997), with attention given to the interplay between choices and actions of participants, their mental health, social norms, and structures (Clark et al., 2008). Data analysis drew on Grounded Theory techniques of open coding, theoretical coding, constant comparison and memo-writing (Corbin & Strauss, 2015; Glaser & Strauss, 1967).

Data analysis of interviews began as soon as the first transcript was available. The first step was to check the accuracy of transcripts against the audio-recordings. Transcripts were read and re-read for familiarity. All qualitative data sources were then analysed using the process described below.

### 6.12.2.1 First phase: open and focused coding

Coding was in two phases. The first phase began with line-by-line open coding, which was carried out inductively. This "breaking data apart" (Corbin & Strauss, 2015) was done with an open mind to consider any possible meanings or implications, as well as factual information related to programme implementation. This phase continued with a closer search for positive and negative mechanisms of change for mothers and volunteers through focused coding. The approach was retroductive: the initial theory of change was used as a heuristic, and additional data to test the developing ideas were then gathered by exploring these theories in subsequent interviews (Astbury & Leeuw, 2010; Wong et al., 2017). This first phase of data analysis was used to support the writing of an evaluation report for NCT at the end of the pilot (McLeish & Hann, 2020).

### 6.12.2.2 Second phase: theoretical coding

The second phase of analysis was detailed theoretical coding of contexts, mechanisms, outcomes, and the relationships between them, for mothers and volunteers. This phase was informed by the initial theory of change and the findings of the realist review, and all data were also coded with *unanticipated* C-M-O configurations. The critical realist question 'what must be true for this to be the case?' was used to theorise abductively how partial C-M-Os could be developed more fully, working backwards from effects to the conditions that would be necessary for those effects to be produced (Jagosh, 2020). The counter-factual questions proposed by Danermark et al. (2002) (e.g. "How would this be if not ... ? Could one imagine X without ... ?") were used to consider essential properties. Maxwell (2012) cautions that qualitative analysis can flatten diversity by focusing on shared themes and concepts, and urges a "deliberate search for variability" (p.66) in critical realist analysis, with a focus on trying to understand the reasons for differences. Particular attention was therefore paid to any findings that were anomalous to the overall patterns, as these could indicate theory failure, an alternative theory, or negative mechanisms.

Reflective memos made during the interviews were revisited, and new memos were used to record developing theoretical ideas and the relationships between them (Charmaz, 2008; Corbin & Strauss, 2015). Constant comparison (Glaser & Strauss, 1967) was used throughout the analysis to consider the similarities and differences between individual interviews, between the interviews from different groups of interviewees, between the three sites, and between codes generated from earlier interviews and those from later interviews.

# 6.13 Developing the final theory of change

The final step in the analysis was the integration of the qualitative and quantitative analyses to answer each research question and create a final theory of change.

This included:

- Bringing together the descriptive quantitative data about take-up and use of peer support with staff explanations of local contextual factors, and their accounts of how and why local adaptations were made at the three sites.
- Considering HADS scores in the light of alternative explanations for changes in mental health drawn from qualitative and quantitative sources.
- Compiling all evidenced positive and negative C-M-O configurations for mothers and volunteers.
- Comparing the final theory of change with the initial theory of change to identify theories that had been added, omitted or altered by the evaluation.

# 6.14 Chapter summary

This chapter has described the mixed methods used in the theory-based process evaluation of Parents in Mind, combining data collected by staff and data collected by the researcher. The next presents part 1 of the results, focusing on the research participants, research question 1 (implementation) and the development of the theory of change.

# 7 Parents in Mind Study - Results, Part 1 (Implementation)

### **Chapter overview**

This chapter presents the first part of the results of the primary research. It describes the Parents in Mind programme, the participants in the quantitative and qualitative research and the development of hypotheses for an initial theory of change. It then presents the results of research question 1, which concerns the action model and implementation of Parents in Mind – the staff; the peer support groups; the volunteers and their recruitment, training, support and retention; the supported mothers and their referral and use of peer support; and the adaptations that were made during the pilot. It concludes by introducing the final theory of change for Parents in Mind.

# 7.1 Setting

This section gives an overview of the Parents in Mind pilot programme.

# 7.1.1 **The peer support model**

In Parents in Mind, peer support from trained, unpaid volunteers was offered to pregnant women and new mothers who were currently experiencing self-defined mild-to-moderate mental health difficulties. The peer supporters were women who had past experience of self-defined perinatal mental health difficulties. The peer support was based around non-directive, strengths-based, active listening; sharing ideas for self-care; and signposting to other sources of support. The underpinning principles were: being non-judgemental; empathy; shared lived experience; trust; confidentiality; respect; and safety.

Parents in Mind offered two types of peer support:

- Groups facilitated by volunteers, where volunteers gave peer support, and mothers gave and received peer support with other group members. The groups did not have a set programme.
- One-to-one, where a mother received individual support from a volunteer in a public place during working hours, usually for up to one hour a week.

# 7.1.2 **The three pilot sites**

The pilot took place at three sites:

# Site 1: Coventry and Warwickshire (September 2016- March 2019)

Coventry has an estimated population of 367,000 and 4,500 births per year (Office for National Statistics, 2017, 2019) A third of its population are from ethnic minorities, principally Asian/British Asian

communities (Coventry City Council, undated). It is among the 20% most deprived areas in England (Ministry of Housing Communities and Local Government, 2019). Warwickshire (population estimate 571,000; 6,000 births per year) is a rural county with 90% of the population from White communities (Warwickshire Observatory, 2014). It is in the 20% least deprived areas (Ministry of Housing Communities and Local Government, 2019).

### Site 2: Widnes and Runcorn (Halton) (January 2017- March 2019)

Halton has an estimated population of 128,000; and 1,500 births per year (Office for National Statistics, 2017, 2019). It has two towns, Runcorn and Widnes, separated by a river and with limited transport links. Almost 98% of the population is White, and it is in the top 10% most deprived areas (Halton Borough Council, undated).

### Site 3: London Borough of Newham (June 2017 – March 2019)

London Borough of Newham is an inner-city area with an estimated population of 352,000 and 6,000 births per year (Office for National Statistics, 2017, 2019). Over half of the population was born outside the UK. A third are from Asian/British Asian communities, nearly a fifth are Black British/African/Caribbean, and one sixth are White British (Newham Info, undated). It is in the top 10% most deprived areas (Ministry of Housing Communities and Local Government, 2019).

### 7.1.3 **Co-production**

Women with lived experience of perinatal mental health difficulties were not part of the original bid for grant funding, but were subsequently involved at every level of the programme, including representation on the advisory group, and programme staff. Volunteers and mothers receiving support were encouraged to co-create the structure and activities of their peer support sessions.

### 7.2 Research participants

### 7.2.1 Routine data collection

Anonymised socio-demographic data were available for 260 mothers referred to Parents in Mind, reported in section 7.4.4.2. Of the 182 mothers who took up peer support, 161 (89%) consented to sharing of their questionnaire answers. Baseline questionnaire data are reported in section 7.4.4.3. There were data from at least one follow-up assessment available for 103 (57%) mothers, reported in section 9.2. There was uneven participation in follow-up data collection across the three sites: 71

mothers (75% of those supported) at site 1, 28 mothers (53% of those supported) at site 2, and 4 mothers (12% of those supported) at site 3.

Anonymised socio-demographic data were available for 77 volunteers, reported in section 7.4.3.1. All volunteers consented to sharing of their pre-training questionnaire answers about their motivation, reported in section 7.4.3.4.

### 7.2.2 Qualitative interviews

Seventy-one interviews were carried out between March 2017 and May 2019:

- (1) Single interviews with 20 supported mothers (site 1 n=10, site 2 n=8, site 3 n=2).
- (2) Single interviews with 27 volunteers (site 1 n=7, site 2 n=9, site 3 n=11).
- (3) Repeat interviews with three local project managers (six interviews at site 1, five at site 2, five at site 3).
- (4) Single interviews with three trainers.
- (5) Repeat interviews with two national project management staff, each interviewed twice.
- (6) Single interview with the peer support team leader at site 1. She had also been interviewed in her previous capacity as a volunteer.

There were 78.5 hours of interviews in total. The mean lengths of interviews were: 37 minutes with mothers (range 20-58 minutes), 54 minutes with volunteers (range 38-82 minutes), 101 minutes with staff (range 36-210 minutes).

Eighteen mothers' interviews were by telephone and two were face-to-face; 26 volunteers' interviews were by telephone and one was face-to-face; and seven of the interviews with staff/trainers were face-to-face, with the rest by telephone.

Thematic saturation was reached with mothers and volunteers at sites 1 and 2, and with volunteers but not mothers at site 3, where only two mothers agreed to their contact details being passed to the researcher.

### 7.2.2.1 Demographic characteristics of interviewees

The demographic characteristics of mothers and volunteers interviewed are shown in Table 9. All staff interviewed were women and were White British (n=7) or White Other (n=2).

	Volunteers (n=27)	Supported mothers (n=20)
Ethnicity		
White British	15 (55.6%)	18 (90%)
White Other	5 (18.5%)	1 (5%)
Asian British	5 (18.5%)	1 (5%)
Black British	1 (3.7%)	0
Black Other	1 (3.7%)	0
Age		
Age 20-30	5 (18.5%)	9 (45%)
Age 31-40	13 (48.2%)	10 (50%)
Age 41-50	7 (25.9%)	1 (5%)
Age 51+	2 (7.4%)	0
Mental health experience	e (current and/or previous)	
Depression	22 (81.5%)	15 (75%)
Anxiety	10 (37%)	18 (90%)
Post-traumatic stress disorder	5 (18.5%)	3 (15%)
Obsessive compulsive disorder	1 (3.7%)	3 (15%)
Other	2 (7.4%)	2 (10%)

# Table 9 Demographic characteristics of mothers and volunteers interviewed

# 7.2.2.2 Interviewees' pseudonyms

Table 10 shows the pseudonyms given to the mothers and volunteers who were interviewed at each site. In quotations from interviews, volunteers are distinguished by the addition of "(V)" after their pseudonym.

### Table 10 Pseudonyms used at each site

	Mothers	Volunteers
Site 1	Annie, Brooke, Cora, Di, Erin, Flo, Grace, Hema, Julie, Keira	Alice, Bridget, Cathy, Deborah, Emilia, Faye, Ginny
Site 2	Lena, Morgan, Natalie, Oona, Paige, Rosie, Sal, Tilly	Helena, Izzy, Josie, Katrin, Laura, Mel, Nina, Olivia, Penny
Site 3	Vicki, Wendy	Quirat, Rachel, Suzie, Tanya, Uma, Vani, Wanda, Xami, Yasmin, Zia, Amy

# 7.3 Initial theory of change hypotheses

Discussions with stakeholders and review of what they had written about the programme revealed a range of implicit theories of how peer support would work. Some believed that it might have a direct impact on symptoms of depression and anxiety, and others predicted that the primary impact would be through motivating mothers to take up mental health treatment, as reflected in a programme overview produced in September 2016: *"Trained perinatal mental health peer supporters have the potential to be real agents for change - promoting positive mental health in their communities, raising awareness, and supporting women experiencing perinatal mental illness to engage with specialist services"*. These theories were incorporated into the draft theory of change alongside theories derived from the literature and prior research experience.

To avoid repetition, the initial theory of change is not presented separately here. The ways in which the C-M-O configurations were altered between the initial and final versions are shown in Table 20 (Chapter 8), Table 23 (Chapter 9) and Table 24 (Chapter 10).

# 7.4 What was implemented in Parents in Mind?

This section reports the results for research question 1, which concerns the action model of the programme: staffing, groups, volunteers, supported mothers and programme adaptations.

### 7.4.1 Staff

A national project manager was employed to lead the programme from March 2016. In June 2018, the funding for this post was reallocated to the sites, in order to extend the end of the pilot from September 2018 to March 2019.

At each site, a part-time (0.6 full time equivalent) local project manager was employed. They had eight core areas of responsibility:

- (1) With volunteers: Organising the recruitment and training of volunteers, supporting and supervising their volunteering (see section 7.4.3.6).
- (2) With supported mothers: Processing referrals, allocating the mother to a group or matching her with a volunteer for one-to-one support, assessing her progress at regular intervals, helping her to access other services.

- (3) With professionals: Networking with professionals in local services (maternity, social care, primary care and mental health) and third sector organisations, to gain their trust and interest in referring mothers, and to establish referral pathways.
- (4) Logistical: Arranging venues for group sessions, organising volunteer rotas, liaising between mothers and volunteers about arrangements for one-to-one sessions, telephoning mothers with reminders of sessions.
- (5) **Publicity:** Advertising the service directly to mothers by developing and distributing flyers and posters, though local media and online.
- (6) **With commissioners:** Promoting Parents in Mind to local commissioners to secure continuation funding.
- (7) **Data collection:** Collecting monitoring data on mothers' mental health, and their feedback as service users.
- (8) Service development: Adapting the service responsively to the local context.

The three local project managers came from varied professional backgrounds – volunteer management, teaching, and community development. They had all experienced self-identified mild perinatal mental health difficulties.

The volunteer training was delivered by three trainers who had completed a two-day, Institute of Health Visitors 'train the trainers' course on perinatal mental health. They were all experienced breastfeeding peer support trainers. Two had also trained volunteers for the NCT's Birth and Beyond Community Supporters programme, in which peer volunteers offered one-to-one support to disadvantaged mothers. None of the trainers had lived experience of perinatal mental health difficulties.

At each site there was a clinical supporter: a mental health professional contracted to assess the mental health of potential volunteers and to be available for support as required.

At site 1, the job of peer support team leader was created in June 2018, when the local project manager took on an additional strategic leadership role. A former volunteer was employed for 10 hours a week to recruit, organise and support volunteers.

### 7.4.2 Peer support groups

At site 1, Parents in Mind volunteers ran three peer support groups in Coventry, Warwick and Leamington, two held in children's centres and one in a private room adjacent to a parent and child drop-in group in a church. At site 2, volunteers ran two peer support groups in children's centres, one in Widnes and one in Runcorn. Site 3 began with two peer support groups in Forest Gate and East Ham held in a children's centre and a community centre run by a third sector organisation. Later one group was replaced with a drop-in (see section 7.5.11).

### 7.4.3 Volunteers

### 7.4.3.1 Socio-demographic characteristics

Seventy seven volunteers took part in the Parents in Mind pilot. The severity of their perinatal mental health experiences ranged from an inpatient stay at a MBU for severe mental illness, to mild difficulties in the transition to parenthood. Table 11 shows their socio-demographic characteristics.

At site 1, two-thirds of volunteers were White British, and they were predominantly more socioeconomically advantaged.

At site 2, almost all volunteers were White British, reflecting the local population, and they were predominantly very socio-economically disadvantaged; a third were currently taking medication for their mental health; and some were dealing with complex circumstances: *"Mental health issues since they were 10, and lots of experience of domestic abuse and financial issues. They bring quite a lot of mental instability and baggage to the table"* (LPM site 2).

At site 3, volunteers were predominantly socio-economically disadvantaged and were from diverse ethnic and cultural backgrounds, reflecting the local population. They spoke thirteen languages besides English.

# Table 11 Characteristics of volunteers

	Site 1 (n=28)	Site 2 (n=24)	Site 3 (n=25)	Total (n=77)
Ethnicity				
White British	18 (64%)	23 (96%)	7 (28%)	48 (62%)
White Other	5 (18%)	0	3 (12%)	7 (9%)
Asian British	3 (11%)	0	6 (24%)	9 (12%)
Black British	0	0	3 (12%)	3 (4%)
Black Other	0	0	4 (16%)	4 (5%)
Mixed & Other	2 (7%)	1 (4%)	2 (8%)	5 (7%)
Additional languages spoken	Arabic, Cantonese, Hindi, Punjabi, Romanian, Spanish	None	Arabic, Bengali, Japanese, Lithuanian, Mandarin, Polish, Punjabi, Russian, Somali, Spanish, Swahili, Tamil, Urdu	Arabic, Bengali, Cantonese, Hindi, Japanese, Lithuanian, Mandarin, Polish, Punjabi, Romanian, Russian, Somali, Spanish, Swahili, Tamil, Urdu
Age				
20-29	3 (11%)	6 (25%)	1 (4%)	10 (13%)
30-39	14 (50%)	8 (33%)	12 (48%)	34 (44%)
40-49	8 (29%)	10 (42%)	9 (36%)	27 (35%)
50-59	2 (7%)	0	2 (8%)	4 (5%)
60+	1 (4%)	0	1 (4%)	2 (3%)
Postcode quintile using	Index of Multiple De	eprivation		
1 (most deprived)	2 (7%)	14 (58%)	8 (32%)	24 (31%)
2	5 (18%)	4 (17%)	12 (48%)	21 (27%)
3	4 (15%)	4 (17%)	3 (12%)	11 (14%)
4	4 (15%)	1 (4%)	0	5 (7%)
5 (least deprived)	12 (43%)	1 (4%)	0	13 (17%)
Missing	1 (4%)	0	2 (8%)	3 (4%)
Mental health at time o	frecruitment			
Taking mental health medication	5 (18%)	9 (32%)	1 (4%)	15 (20%)
Receiving other mental health support	4 (15%)	2 (8%)	3 (12%)	9 (12%)

# 7.4.3.2 Length of participation

Eight cohorts of volunteers were trained, three each at sites 1 and 2 and two at site 3. Table 12 shows how many volunteered and for how long. Of the 77 women who began training, 87% completed the training, and 81% went on to become active volunteers. Of those who began volunteering, 45% were still volunteering two years later.

Because cohorts of volunteers were trained at successive points, there were some who were still volunteering at the end of the pilot but who had finished training less than a year previously. To fairly reflect the commitment of the volunteers, percentages for retention at 1 year and 2 years refer only to those cohorts of volunteers who had been with Parents in Mind for that period.

Recruitment	Site 1 (n=28)	Site 2 (n=24)	Site 3 (n=25)	Total (n=77)
Recruited	28	24	25	77
Finished training	22 (78%)	21 (88%)	24 (96%)	67 (87%)
Became active volunteer	19 (68%)	20 (83%)	23 (92%)	62 (81%)
Retention of active volunteers	Site 1 (n=19)	Site 2 (n=20)	Site 3 (n=23)	Total (n=62)
Retention at 6 months	17 (90%)	14 (70%)	23 (100%)	54 (87%)
Retention at 1 year*	13 (81%)	11 (69%)	6 (50%)	30 (67%)
Retention at 2 years**	8 (50% )	3 (38%)	N/A	11 (45%)

### **Table 12** Recruitment and retention of volunteers

\*At sites 1 and 2, this refers to the first two cohorts only, and at site 3 to the first cohort only

\*\* At site 1 this refers to the first two cohorts only, and at site 2 to the first cohort only

### 7.4.3.3 Recruitment process

Potential volunteers were asked to commit to two hours a week for at least six months. Not all applicants were accepted. As the peer support was based on active listening to mothers in distress, it was essential that volunteers were sufficiently emotionally well to cope with the role, and to offer peer support without using it to meet their own needs. The local project manager interviewed applicants to explore their motivation, their own mental health experience, their support needs and skills. They were also interviewed by the clinical supporter either before or during training. These interviews, and personal reflection during training, enabled some applicants to realise that they were not emotionally ready to volunteer. At sites 1 and 2, a quarter of women who initially asked for information about the

volunteer role went on to start the training, and a third of women at site 3. All volunteers underwent a Disclosure and Barring Service criminal record check.

Local project managers used multiple methods to advertise the volunteering opportunity, including social media; school newsletters; and flyers in children's centres, GP surgeries, clinics, libraries, and supermarket noticeboards. Social media was the most effective method. At site 3 there was also targeted advertising through the local project manager's extensive networks, specifically inviting women from different ethnic minority communities to apply.

# 7.4.3.4 *Motivation*

Volunteers' motivations for wanting to become a peer supporter (as declared during recruitment) were grouped into five categories, shown in Table 13 (for some volunteers, there were two equal primary motivations, so percentages total more than 100%). In this categorisation, 'career development' covered a desire to gain skills and experience or test a career path, and 'personal development' covered a desire to gain knowledge and confidence. Although most volunteers were primarily motivated by altruism, this was true for all volunteers at site 1 but only four-fifths at site 2 and 3, where more of the (predominantly socio-economically disadvantaged) volunteers were motivated by the opportunities for personal or career development.

Main motivation(s)	Site 1 (n=28)	Site 2 (n= 24)	Site 3 (n=25)	All sites (n=77)
Altruism	28 (100%)	19 (79%)	20 (80%)	67 (87%)
Career development	3 (11%)	6 (25%)	7 (28%)	16 (21%)
Personal development	4 (14%)	8 (33%)	5 (20%)	17 (22%)
Meet people	2 (7%)	5 (21%)	1 (4%)	8 (10%)
Other	2 (7%)	0	0	2 (3%)

#### Table 13 Volunteers' main motivations

In interviews, volunteers explained that their altruistic motivation was based on wanting others to avoid the perinatal suffering they had experienced, or to have access to the support they had appreciated: *"I don't want another woman to go through what I went through, and if there's support out there, I'm willing to give it."* (Quirat(V)).

### 7.4.3.5 *Training*

Volunteers initially attended 30 hours of training, in three hour sessions over 10 weeks. This training was accredited by the Open College Network and volunteers could earn a qualification by completing activities and workbooks that were assessed. It was based on three modules focused on perinatal mental health; the biological process of pregnancy, birth and breastfeeding; and group hosting theory. This training was substantially revised during the pilot, as described below in section 7.5.3.

### 7.4.3.6 Support and supervision

Staff recognised the fundamental importance of effective support for their peer supporters, although this took more time than anticipated:

"I think something that we underestimated within the projects is - because we're requesting that lived experience - how much pastoral support some of the volunteers require. If you're asking for someone who's predisposed to mental health problems, they're more susceptible to the ups and downs of their daily life than your average person." (LPM site 2)

Local project managers were in regular individual contact with volunteers, checking in after peer support sessions and inviting volunteers to contact them whenever needed. They also organised regular reflective group sessions to bring the volunteers together for supervision, mutual support, completion of training workbooks, and further training. These were supplemented with a private Facebook or WhatsApp group for volunteers, and other communications to maintain motivation, such as weekly emails about referral numbers and sharing positive feedback from mothers. Individual support from the clinical supporter was available to volunteers on request at any time. Initially the clinical supporters also regularly attended the reflective group sessions. Volunteers' perspectives on how the support helped their emotional wellbeing are in section 10.3.

### 7.4.4 Supported mothers

### 7.4.4.1 Numbers of mothers referred

Across the three sites, 260 mothers were formally referred or self-referred to Parents in Mind during the pilot, and 182 (70%) received support.

Table 14 shows the breakdown by site.

### Table 14 Referrals who were or were not supported

Total referrals	Site 1 (n=139)	Site 2 (n=66)	Site 3 (n=55)	All (n=260)
Referrals who were supported	95 (68%)	53 (80%)	34 (62%)	182 (70%)
Referrals who did not take up support	44 (32%)	13 (20%)	21 (38%)	78 (30%)

# 7.4.4.2 Socio-demographic characteristics

Table 15 shows the socio-demographic characteristics of the 260 mothers who were referred for peer support, separating those who took up support from those who did not. A quarter of mothers who took up peer support were currently pregnant and three-quarters had a young baby. Three-quarters identified their ethnicity as White British. Three-fifths were first time mothers. Three-quarters had a previous history of mental health difficulties, and half were in touch with the perinatal mental health team. A quarter were currently taking mental health medication, and one-fifth were receiving psychological therapy.

There was considerable variation between sites. Mothers who took up support at site 1 were predominantly White British first time mothers, and more socio-economically advantaged than at other sites. Mothers at site 2 were predominantly White British, very socio-economically disadvantaged and already had other children; and a higher proportion were pregnant at the time of referral. Mothers at site 3 were ethnically diverse and more socio-economically disadvantaged; they were less likely to have a history of mental health issues.

There were substantial gaps in the demographic data available for mothers who did not take up support, limiting the reliability of comparison, particularly on ethnicity and age where data were missing for over 20% of mothers who were not supported. With that caveat, mothers who did not take up support after referral were less likely to be a first-time parent, more likely to be a single parent, and less likely to have a previous history of mental health difficulties.

Total	Cite 1 (m-1)	20)	Site 2 (m-S)		Cite 2 (m-4)	2)	All (n=200)	
referrals	Site 1 (n=1)	39)	Site 2 (n=6	<b>b)</b>	Site 3 (n=4	3)	All (n=260)	
	Took up (n=95)	Did not take up (n=44)	Took up (n=53)	Did not take up (n=13)	Took up (n=34)	Did not take up (n=21)	Took up (n=182)	Did not take up (n=78)
Ethnicity	1		-			-	1	
White British	78 (82%)	29 (66%)	48 (91%)	10 (77%)	13 (38%)	0	139 (76%)	39 (50%)
White Other	4 (4%)	1 (2%)	3 (6%)	0	6 (18%)	3 (14%)	13 (7%)	4 (5%)
British Asian	3 (3%)	1 (2%)	0	0	5 (15%)	0	8 (4%)	1 (1%)
Asian Other	1 (1%)	0	0	0	2 (6%)	3 (14%)	3 (2%)	3 (4%)
Black British	2 (2%)	0	0	0	2 (6%)	1 (5%)	4 (2%)	1 (1%)
Black Other	2 (2%)	1 (2%)	0	0	3 (9%)	5 (24%)	5 (3%)	6 (8%)
Mixed/ Other	0	3 (7%)	1 (2%)	1 (8%)	1 (3%)	3 (14%)	2 (1%)	7 (9%)
Not recorded	5 (5%)	9 (20%)	1 (2%)	2 (15%)	2 (6%)	6 (29%)	8 (4%)	17 (22%)
Age								
>20	3 (3%)	2 (5%)	5 (9%)	1 (8%)	2 (6%)	2 (10%)	10 (5%)	5 (6%)
20-29	37 (39%)	19 (43%)	23 (43%)	5 (38%)	7 (21%)	5 (24%)	67 (37%)	29 (37%)
30-39	48 (51%)	13 (30%)	23 (43%)	4 (31%)	22 (65%)	7 (33%)	93 (51%)	24 (31%)
40+	6 (6%)	1 (2%)	2 (4%)	1 (8%)	2 (6%)	0	10 (5%)	2 (3%)
Not recorded	1 (1%)	9 (20%)	0	2 (15%)	1 (3%)	7 (33%)	2 (1%)	18 (23%)
Postcode quint	ile using Inde	ex of Multipl	e Deprivatio	n				
1 (most deprived)	10 (11%)	5 (6%)	34 (64%)	10 (77%)	6 (18%)	4 (19%)	50 (27%)	24 (31%)
2	12 (13%)	29 (37%)	3 (6%)	0	22 (65%)	10 (48%)	27 (20%)	19 (24%)
3	28 (29%)	24 (31%)	2 (4%)	1 (8%)	4 (12%)	1 (5%)	34 (19%)	14 (18%)
4	24 (25%)	2 (3%)	10 (19%)	1 (8%)	0	0	34 (19%)	8 (10%)
5 (least deprived)	20 (21%)	18 (23%)	4 (8%)	1 (8%)	0	0	24 (13%)	13 (17%)
Not recorded	1 (1%)	0	1 (2%)	1 (8%)	2 (6%)	6 (29%)	4 (2%)	10 (13%)
First time pare	nt							
Yes	61 (64%)	13 (30%)	26 (49%)	5 (38%)	19 (56%)	5 (24%)	106 (58%)	23 (29%)
No	34 (36%)	30 (68%)	27 (51%)	6 (46%)	15 (44%)	11 (52%)	76 (42%)	47 (60%)
Not recorded	0	1 (2%)	0	2 (15%)	0	5 (24%)	0	8 (10%)

# **Table 15** Socio-demographic characteristics of all mothers referred to Parents in Mind

# Table 15 continued

Total								
referrals	Site 1 (n=1	39)	Site 2 (n=6	6)	Site 3 (n=4	3)	All (n=260)	
	Took up (n=95)	Did not take up (n=44)	Took up (n=53)	Did not take up (n=13)	Took up (n=34)	Did not take up (n=21)	Took up (n=182)	Did not take up (n=78)
Stage at time of referral								
Pregnant	20 (21%)	16 (36%)	21 (40%)	7 (54%)	5 (15%)	7 (33%)	46 (25%)	30 (38%)
Postnatal	75 (79%)	21 (48%)	32 (60%)	4 (31%)	29 (85%)	8 (38%)	138 (75%)	33 (42%)
Not recorded	0	7 (16%)	0	2 (15%)	0	6 (29%)	0	15 (19%)
Age range of babies	11 days to 16 months	Not recorded	1 month to 17 months	Not recorded	1 week to 14 months	Not recorded	1 week to 17 months	Not recorded
Average baby's age	3 months	Not recorded	4 months	Not recorded	3.5 months	Not recorded	4 months	Not recorded
Partnership sta	tus based or	next of kin	-		-		•	
With a partner	67 (71%)	15 (34%)	36 (68%)	6 (46%)	25 (74%)	5 (24%)	128 (70%)	23 (29%)
Single parent	10 (11%)	4 (9%)	14 (26%)	5 (38%)	4 (12%)	11 (52%)	28 (15%)	47 (60%)
Not recorded	18 (19%)	25 (57%)	3 (6%)	2 (15%)	5 (15%)	5 (24%)	26 (14%)	8 (10%)
Previous histor	y of mental l	nealth issues			-		•	
Yes	74 (78%)	24 (55%)	44 (83%)	9 (69%)	18 (53%)	5 (24%)	136 (75%)	38 (49%)
No	21 (22%)	15 (34%)	9 (17%)	2 (15%)	16 (47%)	8 (38%)	46 (25%)	25 (32%)
Not recorded	0	5 (11%)	0	2 (15%)	0	8 (38%)	0	15 (19%)
Mental health	support at ti	me of referra	al		-		-	
Taking medication	31 (33%)	9 (20%)	13 (25%)	0	5 (15%)	2 (10%)	49 (27%)	11 (14%)
Receiving psychological therapy	24 (25%)	2 (5%)	4 (7%)	3 (23%)	6 (18%)	1 (5%)	34 (19%)	6 (8%)
In touch with perinatal mental health team	54 (57%)	16 (36%)	20 (38%)	3 (23%)	16 (47%)	4 (19%)	90 (50%)	23 (29%)

### 7.4.4.3 Baseline mental health scores

There were baseline Hospital Anxiety and Depression Scale (HADS) scores available for 161 mothers, shown in Table 16.

	Site 1 (n=81)	Site 2 (n=52)	Site 3 (n=28)	All sites (n=161)					
Baseline anxiety score									
Median	12	15	11	13					
Range	2 to 20	5 to 21	3 to 18	2 to 21					
Interquartile range	6	5.75	4	6					
Number (%)	of mothers with	clinically signific	ant baseline anxie	ty scores					
Non-clinical <8	9 (11.1%)	3 (5.8%)	7 (25.0%)	19 (12.0%)					
Mild (8-10)	18 (22.2%)	5 (9.6%)	6 (21.2%)	29 (18.0%)					
Moderate (11-14)	31 (38.3%)	17 (32.7%)	10 (35.7%)	58 (36.0%)					
Severe (15-21)	23 (28.4%)	27 (51.9%)	5 (17.9%)	55 (34.2%)					
	Baseli	ne depression s	core						
Median	8	10	9	9					
Range	0 to 18	0 to 20	3 to 17	0 to 20					
Interquartile range	5	7	5.75	5					
Number (%) o	f mothers with cli	inically significa	nt baseline depress	sion scores					
Non-clinical <8	36 (44.4%)	15 (28.9%)	9 (32.1%)	60 (37.3%)					
Mild (8-10)	24 (29.6%)	18 (34.6%)	11 (39.3%)	53 (32.9%)					
Moderate (11-14)	13 (16.1%)	11 (21.2%)	6 (21.4%)	30 (18.6%)					
Severe (15-21)	8 (9.9%)	8 (15.4%)	2 (7.1%)	18 (11.2%)					

Although Parents in Mind was intended to be for mothers with mild-to-moderate perinatal mental health difficulties, in fact only half of the supported mothers were identified to be in this category using HADS. The range of scores on both the anxiety and the depression subscales were close to the widest range possible (0-21). At all sites, median anxiety scores were higher than median depression scores, and the overall median depression score of 9 suggested clinically significant mild depression, whereas the median anxiety score of 13 suggested moderate anxiety. A third of mothers had scores suggesting severe anxiety.

Both anxiety and depression scores were highest in site 2, where half of mothers had scores suggesting severe anxiety. Site 1 had the highest proportion of mothers with non-clinically significant depression scores, and site 3 had the highest proportion of mothers with non-clinically significant anxiety scores.

# 7.4.4.4 Other mental health issues at referral

Data about other mental health difficulties were available for 161 supported mothers. Across the sites, 11% of mothers were recorded as having post-traumatic stress disorder (PTSD) including birth trauma, 7% had obsessive compulsive disorder (OCD), 5% had borderline personality disorder, and 5% had bipolar disorder, an eating disorder, or alcohol/ drugs dependence.

# 7.4.4.5 *Methods of referral to Parents in Mind*

Table 17 shows how mothers came to use Parents in Mind. Nearly a third of mothers referred themselves without professional involvement, and this was the main form of access at site 3 but little used at site 2. At all sites, a greater proportion of mothers went on to take up peer support following self-referral, compared to professional referral. A quarter of mothers who used support at site 1 (where there was a strong perinatal mental health service) were referred through a mental health team, compared with none at site 3. Midwives were the lead referrers of women who went onto use the peer support at site 2, but were the source of very few successful referrals at site 1. At all sites, midwives accounted for the highest proportion of unsuccessful referrals.

	Site 1 (n=139)	ite 1 (n=139) Site 2 (n=66)		Site 3 (n=43)		All (n=260)		
	Took up (n=95)	Did not take up (n=44)	Took up (n=53)	Did not take up (n=13)	Took up (n=34)	Did not take up (n=21)	Took up (n=182)	Did not take up (n=78)
Self-referral (no professional involvement)	39 (41%)	7 (16%)	8 (15%)	0	21 (62%)	2 (10%)	68 (37%)	9 (12%)
Mental health team	24 (25%)	9 (20%)	7 (13%)	2 (15%)	0	1 (5%)	31 (17%)	12 (15%)
Midwife	7 (7%)	15 (34%)	16 (30%)	6 (46%)	7 (21%)	9 (43%)	30 (16%)	30 (38%)
Health visitor	11 (12%)	6 (14%)	11 (9%)	2 (15%)	2 (6%)	1 (5%)	24 (13%)	9 (12%)
GP	9 (9%)	1 (2%)	1 (2%)	0	0	0	10 (5%)	1 (1%)
Family Nurse Partnership	0	0	4 (7%)	1 (8%)	1 (3%)	0	5 (3%)	1 (1%)
Other	5 (5%)	5 (11%)	6 (11%)	2 (15%)	1 (3%)	1 (5%)	12 (7%)	8 (10%)
Not recorded	0	0	0	0	2 (6%)	0	0	0

### **Table 17** Source of referral or recommendation to Parents in Mind

At each site, before volunteers were recruited, time was invested in building relationships with local professionals who could become referrers, including the development of local steering groups that brought together commissioners and local service providers: *"That groundwork is vital, because unless it's owned and supported by the local community of professionals and everyone else, it will never be accepted as a valid service"* (national project manager). Staff turnover in other services meant that publicising Parents in Mind to professionals had to be an ongoing priority throughout the pilot; this was especially challenging at site 2 where maternity services were provided by four different hospital trusts.

Local project managers reflected on some of the challenges they faced in encouraging referrals or recommendations from different professional groups, in particular the gap between their professed enthusiasm for Parents in Mind and low levels of actual referrals: *"Everyone's shouting about the need for the project but no one's referring in"* (LPM, site 1). They attributed this to various causes, including health professionals' lack of time, the low priority given to peer support, the challenge of reaching frontline practitioners, and the existence of alternative local support groups.

# 7.4.4.6 *Type of peer support used*

Table 18 shows how mothers used the support in various ways, with two-thirds attending a peer support group only. More mothers at site 2 had one-to-one support as well as or instead of group support, whereas the majority of mothers at sites 1 and 3 only had group support. However, at sites 2 and 3, some sessions of groups were attended so sparsely that this 'group' support was closer to a one-to-one: *"We don't have alive groups ...You have two people attending, or no one"* (LPM, site 3).

Type of support	Site 1 (n=95)	Site 2 (n=53)	Site 3 (n=34)	All (n=182)
Group only	83 (87%)	9 (17%)	22 (65%)	114 (63%)
1:1 only	8 (8%)	9 (17%)	8 (24%)	25 (14%)
Group and 1:1	1 (1%)	35 (66%)	3 (9%)	39 (21%)
Support from LPM only	3 (3%)	0	1 (3%)	4 (2%)

#### Table 18 Use of different types of peer support

### 7.4.4.7 *Length of peer support*

Table 19 shows the length of time that mothers used Parents in Mind; these figures are only indicative because they are based on mothers who completed follow-up questionnaires at these time points, whereas some mothers did not complete a final questionnaire when they left the peer support. 43%

received some peer support but did not complete any follow-up questionnaire, suggesting they may have left the peer support before the first follow-up at two months. By contrast, 10% used the support for at least eight months (the fourth follow up).

Time point	Number of mothers (n=182)
1 <sup>st</sup> follow up	103 (57%)
2 <sup>nd</sup> follow up	58 (32%)
3 <sup>rd</sup> follow up	34 (19%)
4 <sup>th</sup> follow up	19 (11%)
5 <sup>th</sup> follow up	10 (6%)
6 <sup>th</sup> follow up	3 (2%)
7 <sup>th</sup> follow up	1 (1%)

**Table 19** Numbers of supported mothers who completed questionnaires at follow-up time points

# 7.5 What adaptations were made and why?

The Parents in Mind pilot was a dynamic learning programme, with innovation and adaptation to local circumstances. There were also adaptions made at a national level in response to evaluation findings and other feedback. This section describes the key adaptations and the reasons for them.

# 7.5.1 Eligibility - mothers

As highlighted in section 7.4.4.3 above, although the intention was that Parents in Mind would be for mothers with mild-to-moderate perinatal mental health difficulties, only half of the supported mothers were identified to be in this category. HADS scores were not used as fixed criteria to include or exclude a mother from peer support. At the initial referral meeting, the local project manager explored the mother's needs, in order to make a joint decision about whether Parents in Mind was right for her. Local project managers used their judgement flexibly, based on what they felt their local volunteers would be able to offer and cope with, and the needs of other mothers in a group. This judgement was not solely about mental health difficulties, but also wider issues such as child protection concerns, and alternative sources of support:

"I have to consider (a) who my volunteers are and what their training has been – I think some of them would be totally scared supporting someone like that [a mother with an abusive partner and six children who were on child protection plans, partly because of her own violence towards them], and (b) I have to consider who else is going to be in group – if that woman came along to the group she's not going to have anything in common with anyone there, which will be an uncomfortable situation for her and them." (LPM site 1)

"She's really higher than our threshold but she's got no family here, no friends, so we are that for her." (LPM site 3)

A second change was that local project managers took an inclusive view of whether mental health difficulties were new and strictly 'perinatal', or a continuation of pre-existing difficulties that created additional challenges for motherhood. This was partly a pragmatic change based on the difficulty of discerning the difference, and partly a compassionate one as mothers with pre-existing difficulties were not eligible for some other services.

"It's very easy on paper to say 'perinatal mental health', as opposed to someone with pre-existing mental health issues who happens to be pregnant – but it's not as black and white as that in reality." (LPM site 1)

"There's nowhere to refer them onto because they also don't meet the criteria for the perinatal mental health team, so we take them." (LPM site 2)

A third change was the adjustment of the age threshold from one year (the normal cut-off for 'perinatal' mental health) to two years after birth. This began spontaneously at sites 1 and 2 when women whose babies had reached 12 months wanted to remain in the group, and continued at site 3 in response to women with older babies asking for support. This led to a formal change in the referral criteria to include any mother with a child under two. In practice, as indicated in Table 15 above, almost all the mothers were within the traditional perinatal period when they started peer support.

### 7.5.2 Eligibility - volunteers

The original pilot plan only made provision for training one cohort of volunteers at each site, but attrition meant that the programme would have become unsustainable by the second year without more volunteers. Extra funding was secured at all sites to train additional cohorts. Local project managers suggested that ideally there would be recurrent annual training of 10-12 volunteers, with the expectation that eight would go on to actively volunteer.

Recruitment criteria for volunteers evolved from the initial assumption that they should have personal experience of perinatal mental health difficulties from which they had recovered. As highlighted in

section 7.4.3.1, a fifth of volunteers said they were currently managing their mental health through medication and some were currently receiving another form of mental health support. Particularly at site 3, a few volunteers had very young babies and were still dealing with current mild perinatal mental health difficulties. Fluctuating mental health meant that some volunteers were not always able to meet their commitments to the training or volunteering, particularly if they were also dealing with other forms of disadvantage: *"It's not about the grades you got but your willingness to turn up to stuff ...* [During training] some had the attitude, *'I'm ill this week, it's not my problem.'"* (LPM site 2). They were also more vulnerable to experiencing emotional distress during peer support: *"If they've recovered more, it's better, you're not on the phone giving them support all the time because they're triggered"* (LPM site 3). Irregular volunteering at site 3 may have contributed to low attendance at groups and limited self-disclosure by mothers: *"The issue is not that they don't want to [open up] but that they're not comfortable to, because they know that volunteer won't be there next week"* (LPM site 3).

The definition of who had 'peer' lived experience was also widened away from strict personal experience of perinatal mental health difficulties. As with the supported mothers, it came to include some volunteers who had ongoing poor mental health in the perinatal period in the context of lifelong difficulties. It also came to include some who had experienced very mild difficulties; some who had experienced mental health difficulties only outside the perinatal period; and a few who had other relevant experience such as supporting a close friend or relative with perinatal mental health difficulties. This adaptation was made because local project managers found that volunteers with more limited lived experience of perinatal mental health difficulties were just as likely to be empathetic and non-judgemental if they were by nature open and inclusive. These volunteers also tended to stay with Parents in Mind longer, and to be more dependable and flexible.

"The best volunteers, in terms of reliability, resilience, and going and getting on with it, are the people who have had the least severe symptoms, or even people you would not describe as having had traditional 'perinatal mental health problems' ... In saying you need lived experience you're pushing a black-and-white, 'Are you judgemental or are you not, if you've lived it you can't be'. But some of the volunteers don't fit as neatly into that black-and-white and yet they are some of the most nonjudgemental volunteers I've got." (LPM site 2)

This change widened the pool of potential applicants and shifted the emphasis in recruitment to careful assessment of all potential volunteers' aptitude, skills, motivation and values, including having a non-

judgemental attitude to issues beyond mental health (for example, immigration and other cultures) and commitment.

"It's looking at the individual's understanding, empathy and communication skills...Those whose previous jobs have equipped them [with skills], do stand out as the 'best' volunteers – but that's not to say the others aren't able to do the role. People just have to have a real mixture of skills – being very adaptable, having a good degree of common sense and confidence." (LPM site 1)

At site 2, an additional reason for widening the criteria was that recruitment was difficult after the first cohort, because there were far fewer births per year: *"How many of those 1,500 mothers will identify with having had lived experience, and how many are sufficiently past that point that they can offer support, and then within that how many can make a Tuesday at half past nine?"* (LPM site 2).

#### 7.5.3 **Training**

The volunteer training was reviewed after the first year, to align more closely with the peer support that was being delivered, and to improve volunteer wellbeing. The course was reduced from 30 hours over 10 weeks to 24 hours over 8 weeks. The content of the training was substantially revised, with greater focus on self-care, cultural differences, and the practical aspects of group hosting. The detailed content on the physiology of pregnancy, birth and breastfeeding was reduced, and these topics were linked more directly to mental health. Trainees were given case studies drawn from real peer support situations that had arisen. There was clarification of what had been a confusing message about the meaning of active listening: *"We were to sit quietly and let them talk and we shouldn't talk. … [The trainer] was saying the least questions you ask, the better. And I just didn't feel that was right."* (Izzy(V)). The appropriateness of volunteers describing their own mental health experiences during peer support was also clarified (see section 7.5.10).

#### 7.5.4 **Reflective group sessions and clinical support**

Reflective group sessions were held every one or two months, and were initially led by the trainer, clinical supporter or local project manager. There were criticisms from volunteers that these sessions were a missed opportunity for mutual support, because they were more focused on Open College Network paperwork, a clinical view of individual mothers' mental health, or process issues. Attendance was generally low, in part because of volunteers' family or work responsibilities, but also because the sessions were not necessarily seen as useful enough to be a priority. In response to volunteer feedback (which is explored in Chapter 10), by the end of the pilot the focus of the group sessions had been adjusted to reduce the input of the trainer and clinical supporter and to increase the opportunity for

volunteers to engage in meaningful reflection and mutual support. At site 2, routine conversations every few months with the clinical supporter were introduced for all volunteers, as a regular check that they remained sufficiently well to volunteer safely, because their emotional wellbeing fluctuated considerably: *"These women are giving up their time and have such a passion to make a difference to people, and we've got a total obligation to make sure that they're fit and well before they go out"* (LPM site 2).

#### 7.5.5 Structure, length and ending

There were contrasting views about how to balance informality against structure, and building peer support relationships against the risk of dependency. At the outset there was no limit on the number of peer support sessions that a mother could attend. During the pilot, a pathway was developed at sites 1 and 2 to encourage mothers to see Parents in Mind as a service that would offer them a set of eight sessions and then a review, with a possibility of another set of sessions if needed. Staff felt this helped to (1) manage mothers' expectations, and thus make the concept of moving on less uncomfortable; (2) particularly at site 2, to put a 'value' on each session in order to reduce the number of mothers not turning up for one-to-one sessions, which was demoralising for volunteers; (3) manage capacity issues when there were lots of referrals, avoiding the need for a waiting list. At site 3 there was no defined number of sessions, because it was felt that peer support should be available to mothers (particularly those with multiple disadvantages) for as long as they were deriving benefit: *"Who am I to say to somebody, 'You've had your quota, you're ready to move on'?"* (LPM, site 3).The practicality of this had not been tested as low take-up meant there were no capacity problems at site 3.

Site 2 also developed a pathway where all mothers were offered some one-to-one support before later transition to a group. There was concern about dependency within one-to-one relationships at this site, so volunteers would be swapped around after a 'set' of one-to-one sessions *"so you're not building too much of a crutch with one person"* (LPM site 2). There was very limited attendance at the peer support groups, and these were reconceptualised to try to alleviate mothers' concerns about the group format: *"It's an informal drop-in session, a slight extension of the one-to-one ... there's four volunteers so you can take one aside and have that one-to-one conversation, but equally you've got that broader opportunity to talk to other women"* (LPM site 2). At site 3, there was a different emphasis for the one-to-one support: *"It's relationship: that's where the peer support magic happens. I wouldn't even consider changing the volunteer if things are working"* (LPM site 3). Likewise site 1 did not adopt the sequential approach used in site 2: *"The majority of people who want one-to-one will never go into the group.* 

Sometimes they do, but only in specific circumstances where their main issue is fear of going places" (LPM site 1).

These adaptations were connected with how staff saw the purpose of peer support. Some saw it as a transitional phase into other services or support: *"Although that transition couldn't happen without peer support, we're talking about it being a 2, 3, 4 month programme … if it's doing what it should be doing, people should be moving on by that point' …Our whole aim is that you don't need us anymore"* (LPM site 2). Others saw it as a place where mothers with perinatal mental health difficulties may feel uniquely at home in a way that would not be replicated in other services: *"That woman came and found a little tribe, even as an experienced facilitator I would struggle with telling her it's time to go"* (trainer, site 1).

#### 7.5.6 **Resource toolkit**

In the second year of the pilot the local project manager at site 2 created a toolkit of ten self-care resources for volunteers to share with mothers. These included hand-outs with short activities and apps and podcasts covering mental health topics. Volunteers at site 2 were enthusiastic about having something specific to offer mothers, which also added some structure to their conversation. Mothers at site 2 were less enthusiastic: *"They don't want to take them"* (LPM site 2). The local project manager asked volunteers to introduce one of these resources to mothers at each session, *"even if they put them at the bottom of their handbag or make a hat out of them ... It's about keeping that self-help strand alive and encourages volunteers to ask women what else they've done to look after themselves in the week, to spot their own systems and structures"* (LPM site 2). This adaptation was used flexibly at site 1, but was abandoned at site 3: *"The toolkit of resources, it's just not for our women. They find it too structured ...Some peer supporters used a couple of techniques with a small group but felt that there was a lot of explanation required due to language barriers and difference in cultural experiences, and this took away from the aim of the process" (LPM site 3).* 

### 7.5.7 **Telephones**

For most of the pilot, Parents in Mind support was only offered face-to-face, and volunteers were not allowed to have contact with supported mothers by telephone, which meant that all changes in arrangements had to be made through the local project manager. This proved to be an inefficient system that created a large logistical burden for the local project managers, exacerbated by the fact that their roles were part-time. The lack of telephone support was also felt to undermine inclusivity (see sections 8.4.1 and 8.6) and volunteers' ability to build strong peer support relationships. However, there

was opposition to the introduction of phones from the head office of NCT, based on concerns about how this could be safely managed, which the local project managers believed to be unfounded:

"There's people in NCT who don't have an understanding of mental health. I often feel when I'm talking to them like they've got this image of a Parents in Mind woman who's walking around with a knife in her pocket, about to slit her throat, or is about to jump off every bridge that she sees." (LPM, site 1)

Near the end of the pilot, volunteers in site 2 were allowed to trial the use of mobile telephones to make arrangements and to give peer support at a pre-arranged time. At site 3, the volunteers unexpectedly chose not to use telephones when this option was offered to them: *"They didn't want responsibility of having to look at phone all the time to see if someone's contacted them"* (LPM site 3).

### 7.5.8 Terminology

The three sites adapted the language of their publicity to their local communities. Sites 1 and 2 used a mixture of terms including 'mental health', 'low mood', 'anxiety', and 'emotional difficulty', with the intention of making it clear that the support was aimed at mothers who were struggling emotionally. At site 3, the terminology used in publicity materials was 'feeling low, anxious, alone'. The words 'mental health' were deliberately avoided because some site 3 communities would not identify with those terms. It was also believed that using the term 'mental health' would attract mothers with a formal diagnosis and that these mothers might be too unwell to be supported by Parents in Mind. Mothers who used Parents in Mind at site 3 did indeed have lower initial mean anxiety and depression scores than at the other sites, as described in section 7.4.4.3.

### 7.5.9 **Role of the local project manager**

The role of the local project manager quickly evolved to include aspects of work that were not foreseen in the original plan. This included acting as a peer supporter when volunteers were not available or where the mother's needs might be too challenging for volunteers. The local project manager at site 3 had undertaken the Parents in Mind training, while the local project managers at sites 1 and 2 had been present for the training without taking part.

Some mothers who attended an initial referral meeting had needs that were beyond the remit of Parents in Mind. In these cases, the local project managers invested significant time in finding appropriate services and advocating on the mother's behalf, particularly where she had previously been turned down by a service. "She really wasn't doing well. The health visitor had referred her to perinatal mental health but she'd been turned down... However, after speaking to her about traumatic birth and fairly clear signs of severe postnatal depression and anxiety, I supported her to get the health visitor to re-refer and meanwhile spoke to the perinatal mental health team... she was then admitted to the MBU." (LPM site 1)

Likewise if a mother receiving peer support became too unwell for it to safely continue, the local project manager tried to ensure that she received professional support instead.

"I was absolutely aghast to ring the crisis team on behalf of this lady and receive an automated voice message at quarter to four in the afternoon saying 'You are ringing out of hours'. And that really terrified me thinking, 'If that was the lady herself ringing...?' It took me nine phone calls to actually raise anybody." (LPM site 2)

This role, working with mothers and volunteers with a range of mental health difficulties and having responsibility for ensuring that everyone continued to be well enough to participate, was emotionally demanding, and challenging to fit into a part-time week: *"Ultimately this is a human being and you can't just say 'It's Wednesday night, I'll leave you to it'"* (LPM site 2). The local project managers found that mutually supportive relationships with the each other (and at one site, with the trainer) were very helpful. They suggested that they should also have access to clinical support if needed, from a professional not connected with Parents in Mind.

### 7.5.10 Volunteers talking about their lived experience

### 7.5.10.1 'It's forbidden to talk about your journey'

The original volunteer training had drawn its peer support theory from the NCT's established breastfeeding peer support programme: "When I discuss what Parents in Mind needs, [my colleague] always says 'Well, in breastfeeding peer support we always do this" (national project manager). This included the apparent principle that peer supporters should <u>not</u> talk about their own mental health experiences, although not all the trainers taught this as a blanket prohibition: "If you won't say anything about yourself, you're not real. It's sharing to show your understanding, not sharing to say 'I did this and you should do it as well' ... [But] in looking at what they needed to achieve in a role play, the workbook said very clearly 'did not share own experience'" (trainer, site 3).

This mixed message was reflected in divergent (and confused) views among the volunteers who attended the original training about whether – and how – they should mention their personal experience of perinatal mental health difficulties during peer support, as illustrated by the contrast

between Alice(V): "We never discuss what happened to us or our individual cases", and Laura(V): "We can disclose to them as much as we want."

Most volunteers had understood from their training a variety of reasons why peer supporters should not share their own experiences in detail:

- A belief that feeling able to speak honestly and gain emotional release was the core mechanism of peer support, and that the volunteer's role should be therefore be <u>limited</u> to active listening to enable mothers to work through their own problems by talking about them: *"I went into it thinking I was going to be able to share my experience to other mums. But as the training went on, it became more apparent that that wasn't necessary, all I needed to do was listen"* (Olivia(V)).
- The risk that the volunteer would use peer support to meet her own needs, instead of keeping the focus on the mother: "*Part of the training is that it's not about us, it's about them and what they're going through"* (Ginny(V)).
- The risk that the volunteer would advise the mother to try the things the volunteer had found useful, forgetting that these were not necessarily transferable: *"Although it may be quite similar, we are living different lives, we have different home circumstances"* (Suzie(V)).
- The risk that a mother would use the peer's experience inappropriately to help her make decisions about her own mental health treatment. Despite her best efforts to make it clear that different treatments work for different people, this had happened to Izzy(V): "[A mother] asked my views on [named medication] ... I told her what happened to me. I said, 'But for you it could be totally different. You need to speak to your doctor'... I mentioned I had had [CBT] and it didn't work for me but again, everybody is different. It could work for you or it could not work for you. Also, it could work for me in the years down the line. But she latched on to what I was saying, and she thought, 'I'm going to give CBT up and go on [named medication] and get better."
- The risk that if the mother believed she had been given advice, that would undermine the mechanism of empowerment (see section 9.3.4): "It's not helpful for us to give that advice; we're givers of information, and we're empowering these women to then say, 'How I then decide to use that information is up to me'" (Penny(V)).

In practice, some volunteers felt that the prohibition on sharing their lived experience had undermined their ability to make authentic relationships with mothers: *"If we just sit there nodding there's an element of, 'Are you actually listening? Q: So to make it a real relationship, you have to give something back? A: Exactly, to make it reciprocal"* (Penny(V)). Mothers who gave feedback at site 3 endorsed this

view: "Good volunteer support feels like a relationship, not a service... [The mothers] felt they weren't building a relationship enough because the volunteers weren't sharing" (LPM site 3).

One year into the pilot, it became apparent that there was a serious discrepancy between the Parents in Mind approach as understood by most volunteers, and the definition of perinatal mental health peer support in other organisations. Two volunteers attended a consultation event for the development of quality standards for perinatal mental health peer support (McPin Foundation, 2018) and publically explained what they understood to be the Parents in Mind approach to using lived experience: *"They said, 'We don't talk about it.'... One even used the word 'forbidden', it's forbidden to talk about your own journey. And people there were aghast, and said 'That's not peer support!'"* (LPM, site 2).

#### 7.5.10.2 Talking about personal experience within boundaries

Subsequent open discussion of this issue clarified Parents in Mind's position, and this was incorporated into the revised training that was developed shortly afterwards: volunteers were encouraged to share their lived experience, within boundaries that excluded talking about mental health treatments or giving advice based on their own experience. This helped to reassure volunteers who had been confused or had clandestinely done what they believed to be the right thing.

"I told them that it's ok to share but it just has to be appropriate and not medical ... As long as you're not monopolising the conversation with your story, then if the mother says something where you can chime in and make her feel less alone and more supported, crack on!" (LPM site 2)

Anything other than a prohibition on sharing personal experience required volunteers to use their judgment. While the local project managers believed that appropriate sharing was an essential part of peer support, they did have concerns that not all volunteers could navigate the boundaries effectively, and they emphasised the importance of careful recruitment, training and ongoing supervision to ensure mothers received high quality peer support:

"My worry about advice is that 70% of my volunteers I would wholeheartedly trust to give advice in a supportive, nurturing way, and not to say, 'That medication you've been put on is rubbish, because I was so ill'... But I don't think it's a blanket skill that everyone has." (LPM site 2)

#### 7.5.11 Site 3 adaptations

At site 3, Parents in Mind was closely embedded in the NCT branch (a volunteer-run community group for parents, affiliated to the national charity) because the local project manager was also the branch coordinator, who had a high profile as a local maternity services champion, with good connections to potential referrers, and a social media network that reached potential volunteers and women needing support: *"For many health professionals it's just an extension of Newham NCT running Parents in Mind, because I've built relationships with them for the past 5 ½ years"* (LPM site 3). Despite these connections, site 3 faced considerable challenges with encouraging uptake of peer support, particularly by mothers from ethnic minorities and mothers experiencing severe or multiple disadvantages, and the possible reasons for this are discussed in sections 8.5 and 8.6. As shown in section 7.4.4.2, although mothers who took up peer support at site 3 were more ethnically diverse than at sites 1 and 2, they did not fully reflect the ethnic diversity and socio-economic disadvantage of the borough. In addition, even for mothers who took up peer support, ongoing engagement with both one-to-one and group support was very low, although there was sustained engagement from a small number of White British mothers from more advantaged socio-economic backgrounds:

"Any of BME [Black and minority ethnic] community that were coming in, anyone with multiple disadvantage, were not staying in the service... The very small groups that I have are White British, and yes we're supporting them, but that's not OK because my community is only 16% White British ... The service model doesn't work for the demographic that I'm in." (LPM site 3)

Erratic attendance and high drop-out from groups was mirrored by some mothers choosing not to continue one-to-one support after the initial meeting with their volunteer. As noted in section 7.2.1 above, only four mothers at site 3 participated in follow-up data collection at approximately two months after they began using the support, which is likely to be a reflection of the low numbers who remained sufficiently in touch with Parents in Mind at that point.

The pilot period was therefore used to try out other ways of taking peer support to mothers. Adaptations at site 3 included a drop-in group accessed without a referral process, and Parents in Mind volunteers attending an NCT breastfeeding drop-in group and two playgroups for families with housing problems or in food poverty, to offer support opportunistically. These opportunistic conversations were referred to within Parents in Mind as 'floating support', but it was not clear that it constituted meaningful peer support: "Because a lot of people are around, they're just talking surfacely about how things are hard, the volunteer may be sharing a little about how she felt ...It may not be safe and effective, but it's available" (LPM site 3). At the breastfeeding drop-in group there was a break-out room which provided the possibility of more private conversations about mental health. These innovations occurred too late in the pilot to be evaluated.

# 7.6 Final theory of change

The final theory of change for Parents in Mind is shown in Figures 6 to 11. Figure 6 appears below, and the linked figures appear at the start of the chapters containing the relevant narrative results: Figure 7 (take-up) in Chapter 8; Figure 8 (positive C-M-Os for mothers) and Figure 9 (negative C-M-Os for mothers) in Chapter 9; and Figure 10 (positive C-M-Os for volunteers) and Figure 11 (negative C-M-Os for volunteers) in Chapter 10.



# 7.7 Chapter summary

This chapter has presented the first part of the results of the primary research, focusing on the setting for the research, research participants, the development of the theory of change, and the implementation of Parents in Mind. The three sites had different socio-demographic contexts, and mothers who made use of peer support had a range of mental health difficulties, dominated by anxiety. Adaptations were made during the pilot in response to local contextual factors and iterative learning, affecting eligibility, volunteer training and support, the structure and length of the peer support, using telephones, the mental health terminology used, the role of the local project manager, and the way that volunteers' could speak about their lived experience. The next chapter presents the second part of the results, focused on research questions 2 (take-up) and 5 (group or one-to-one).

# 8 Parents in Mind Study - Results, Part 2 (Take-up)

### **Chapter overview**

This chapter presents the second part of the results of the primary research, answering research questions 2 (take-up) and 5 (group or one-to-one). It begins with an overview of the final theory of change related to mothers' take-up of peer support. It reports the contextual factors and mechanisms related to mothers' beliefs about the benefits of peer support, and the ways in which the opportunity to use peer support was affected by support from health professionals and the format in which the peer support was offered. Finally it examines the ways in which factors related to socio-demographic background may affect a mother's decision about using peer support.

# 8.1 Theory of change for the take-up of peer support: introduction

This chapter explores the mechanisms that affect participation in Parents in Mind peer support in different contexts. An overview of the final theory of change related to mothers taking up peer support is shown in Figure 7, followed by a narrative description of these theories and the evidence used to derive them. In all cases the 'resources' aspect of the mechanism is the offer of peer support, and the outcome is the decision to use peer support. In the narrative sections, contextual factors and mechanisms are identified by (C) and (M).

This analysis is based on mothers' open text answers to the question '*What are you hoping to get out of peer support?*' in their initial questionnaires, and on interviews with mothers, volunteers and staff. The open text answers were used to gain an understanding of the motivations of all the mothers who took part in the Parents in Mind pilot, whereas the qualitative interviews offered an opportunity to explore these topics in greater depth with a smaller number of mothers. This chapter primarily relies on explanations from mothers about why they <u>did</u> take up peer support, and on the explanations from staff and volunteers about why other mothers <u>did not</u> take up peer support. In order to protect confidentiality, the pseudonyms of the volunteers are omitted where the ethnicity of the volunteer is included in an explanation relating to culture.
#### Figure 7 Contexts and mechanisms connected to the outcome of take-up



# 8.2 Expectations of benefit

### 8.2.1 Stigma, shame and the desire to speak freely

### 8.2.1.1 Context: the 'myth of motherhood' and mental health stigma

Many mothers spoke of how the prevailing social narrative of contented motherhood had conditioned their expectations (C), and how their experienced reality of sleeplessness, pain, birth trauma, breastfeeding difficulties, stress, anxiety, and unhappiness had made them feel abnormal and ashamed (C). Some said that although they were aware in a general sense that motherhood might not be *"sunshine and rainbows and daisies"* (Erin), this had not prepared them for the reality: *"I expected it to be challenging and testing and tiring, but no-one prepared me <u>fully</u> for what birth and breastfeeding could be like" (Grace). They consequently felt separated by their experiences and emotions from 'normal' parents, and believed that they had 'failed' where others apparently 'succeeded': <i>"When you're feeling low, you think, 'How come it's perfect for everyone else?'"* (Hema). They referred to the social unacceptability of expressing maternal discontent (C):

"There's a lot of pressure on mums and a lot of expectation that it should be the best time of your life ... People expect you to be on cloud nine with this new baby and I just wasn't feeling it at all." (Rosie)

Mothers saw perinatal mental health difficulties as particularly stigmatised (C): *"It is taboo, postnatal depression... people think of it as, you don't love your baby"* (Paige). Many had strongly internalised this stigma and expressed it as 'guilt' (C), a self-criticism that was particularly acute where the pregnancy was longed-for:

"I felt intensely guilty that I'd been given what we'd been wanting for years, and why wasn't I happy?... I felt like a complete failure, like my son and my husband would be so much better off without me." (Grace)

Some mothers said that social media had intensified their feelings of alienation because other mothers selectively presented their lives as idyllic: "You see things on Facebook with mums saying stupid stuff that I believed, like 'Oh I loved doing the night feeds'... and how blessed they are. You know, #blessed" (Paige). They had also encountered uncomfortable portrayals of what appeared to be perfection in 'normal' parent and child groups (C): "In some toddler groups ... a lot of mums can give the impression that their lives are perfect and little Tarquin or whoever is a dream" (Grace). When other parents admitted to difficulties but placed them in an overall positive narrative, this did not validate mothers' feelings of unhappiness and anxiety: "There's a huge problem of people saying, 'This was really bad, but oh, once you look in their eyes, it's so worth it' ... they just brush off all the horrendous things" (Erin). Some mothers located the root of their shame in their own pride or perfectionism, suggesting a contextual factor at the level of their individual personality (C), although inevitably this was also connected to their beliefs about what was 'normal'.

"I felt really guilty ... I think [it was] just my personality, the way I am. All through my life, at school and my career, I've always struggled with not doing things as well as I want to do them. So, I think it came more from my own expectations of myself ... I don't think it came from external sources" (Di).

These contextual issues were not universal among the mothers who took up peer support. In particular many mothers had pre-existing mental health difficulties, and did not necessarily experience their perinatal feelings as different, so there was no specific sense of motherhood failure: *"I've always had anxiety. When I was pregnant, it seemed to just take a turn for the worse. That's when I went to the doctor's to get more help"* (Annie). There were also mothers dealing with multiple disadvantages and the long term psychological impact of trauma such as physical or sexual assault or the violent death a relative. These mothers were not concerned with trying to maintain 'face' but simply trying to survive:

"My ex-husband broke my son's leg, and he was the reason for me to bury two babies ... I went through a very bad spiral. I had three kids to look after on my own, and I had lost my house and everything, had social workers, they were going to take my kids off me, so I had to prove myself... [Then my baby] came at 29 weeks, and they told us he was going to be paralysed ... I started feeling really suicidal" (Morgan).

# 8.2.1.2 *Context: mothers do not turn to family & friends*

Many mothers had concealed their feelings from family and friends, for fear of being judged (C): "I don't want to be looked upon in a negative way, so I've always been desperate to hide it from people" (Cora). Some referred to this as 'putting on a mask' to hide their true feelings: "I've not told a single member of my family, none of them know what I've been going through... I can put on a bit of a face and act like everything's great... but when you take away my red lipstick and my make-up, I was dying inside" (Hema). Mothers worried about the repercussions on their social relationships if they disclosed their feelings to those close to them, and worried that there was no guarantee of confidentiality: "If it was a friend, you've got so much more to lose, and they could go and tell someone else, and all of a sudden people are looking down [on you]" (Brooke). Some mothers had stopped being honest about their feelings when they experienced direct criticism from their social circle: "I had quite a judgmental partner and his family were very judgmental, everybody had an opinion" (Oona). Likewise the mothers who socialised with other new mothers in 'normal' parent and baby groups had not felt able to talk about their true feelings, either because they felt pressure to present themselves in a good light (C): *"In the other groups you almost feel like you have to say the most positive version of everything"* (Di); or the generally superficial nature of these encounters: *"You just go to play with the children and meet people, but you never have the conversations that are beyond 'How did they sleep last night?'"* (Flo). This self-silencing was influenced both by internalised stigma and expectations of social stigma: *"If I went to any other mums' groups, sometimes it feels as though there is an element of judgment, and I couldn't communicate how I was feeling as a parent openly. I felt so ashamed of how I was feeling"* (Natalie).

A few mothers said that family or friends were aware of their mental health difficulties, but they did not rely on them as an emotional resource. This could be because people who had not experienced perinatal mental health difficulties did not understand and could not give useful suggestions for coping (C). For example Erin had tried to explain to friends that she was unhappy when she was pregnant, but they had absorbed the positive motherhood stereotypes: "For me to say things like, 'I'm having a rubbish time', they were saying, 'Isn't this supposed to be magical?' ... And they couldn't understand it, because it's seen as pregnancy and babies was happy adverts and Hollywood films." She also felt inhibited from disclosing the full extent of her feelings because she was worried about upsetting people who might have hidden sensitivities (C): "Ranting about being pregnant is risky in an environment where perhaps people are struggling to get pregnant or suffering from a loss." Some mothers had found that although the reaction of family and friends was intended kindly, it was not empathetic: "Friends and my partner tend to treat you differently when you open up to them about how you're feeling inside, they treat you a bit like glass" (Julie). Family and friends might be invested in the situation and try to solve it in ways that were unhelpful (C): "Most of my problems are around my ex-partner and I felt like, if I was telling my family, they'd start, 'Ah, he needs to do this, and I'm going to tell this person.' And then I'd start holding back and thinking, 'I can't be doing with the hassle. I've got enough to deal with, without you going off on one as well'" (Sal). Alternatively some mothers wanted to protect members of their social circle who had their own problems (C): "Everyone has their own stuff going on, and I don't like to burden them ...They know I have problems, but I don't go to them if I have a bad day" (Keira).

# 8.2.1.3 *Context: mothers do not turn to their partners*

All the mothers who were interviewed and had a partner said they had told their partner how they felt, and recognised that this could cause them intense stress: *"There was a period of time where he was quite fearful of going to work, because he wasn't sure if he'd come back to find me dead or alive"* 

(Natalie). Most reported that their partners were supportive in practical ways, for example looking after the baby, but did not empathise with their mental health difficulties (C): *"He doesn't understand. He's seen me have two panic attacks and he's like, 'You should just calm down'"* (Brooke). Some had tried to protect their partners from their daily distress, particularly if the partner had his own mental health difficulties (C): *"He was adjusting to being a dad and he didn't find that particularly easy either. I didn't feel like I wanted to keep off-loading on him"* (Di).

### 8.2.1.4 *Context: beliefs about the causes of perinatal mental health difficulties*

It was hypothesised in the initial theory of change that mothers' personal beliefs about the cause of their perinatal mental health difficulties might affect their perception of peer support as a useful response, with mothers who took a biomedical perspective being more likely to turn to a pharmacological solution, mothers who took a psychological perspective being more likely to see talking and listening as a relevant response, and mothers who took a social perspective wanting practical solutions to their difficulties. This hypothesis was not borne out by the interviews at all. Mothers who had taken up peer support gave a wide range of bio-psycho-social attributions for their poor mental health, including perinatal hormones; physical health problems during pregnancy or afterwards; difficult birth experiences; overload and exhaustion (sometimes linked to exclusive breastfeeding or an unsupportive partner); a feeling of failure about unsuccessful breastfeeding; difficulties with role transition including missing the structure and validation of work and feeling a loss of identity and control; domestic abuse; isolation; difficult relationships with family and in-laws; worries about their children's involvement with safeguarding proceedings; their past mental health history; and maladaptive coping strategies. Brooke rejected the label of mental health difficulties completely: "It's not a mental health issue, it's just the way that I'm built." Many mothers understood their poor mental health as the product of multiple interacting factors, past and present, for example:

"It's like something is wrong in my brain, it feels a bit broken... I guess I am predisposed to it, given my mental health in the past. The birth wasn't great. I ended up having to be induced for days, then epidurals and ultimately a C-section. I had an infection in that later, which was hard to heal and I couldn't hold my son as much as I wanted to. Also, just breastfeeding. I really wanted to breastfeed but I had low milk supply and I felt like a failure that he had to have formula." (Lena)

"I've always had history of depression and anxiety, OCD, so I think it was bound to happen ... Physically I was very ill as well, I had a transfusion, I was severely anaemic, I had stitches and they ripped open after three days and they stitched me back up and I was in a very bad way ... Some of the anxiety is my personality. Some of it is because I had a bad childhood ... I was always known for being immaculately turned out, makeup perfect, hair perfect, high heels and matching handbags. And I was never late for anything and I'm known for being dead organised in work ... Now the house is always a mess. So this person, sitting looking like this with no makeup, it's not me." (Paige)

When staff and volunteers sought to explain the low uptake of peer support by mothers from Black, Asian and other ethnic minority communities at site 3, they frequently cited community attitudes to the concept of mental health difficulties and the validity of talking about feelings. These theories are explored in section 8.5 below.

# 8.2.1.5 *Mechanisms: wanting to talk openly and be understood non-judgmentally*

It was clear from the open text comments and interviews that the contextual factors described above had triggered the mechanisms that had motivated many mothers to take up peer support: they had a strong desire to talk honestly about their pent-up feelings (M) and believed that peer support would be a place where they could *"speak to people honestly and therefore gain a sense of relief"* (CW110). They believed that peers would be empathetically understanding (M) and nonjudgmentally accepting (M):

"I wanted to find people that would understand, because in my day-to-day life there wasn't really anyone else, like new mums that seemed to have the same issues. It was hard to fit in." (Lena).

"A group to go to where I can be honest about the fact I'm struggling and don't have to be 'preened'. Want a space where I won't be judged and I can get to know other people who are struggling." (CW36)

However, not all mothers believed that being a mental health peer would guarantee empathy and acceptance. For example, Oona said she avoided the peer support group because she expected to be judged by the others there, although she felt safe talking to a volunteer alone: "I have a really negative association with being pregnant and having a baby, my body image and how I felt about myself (C). I think I projected that onto other people and assumed that's what they thought about me (M)". Likewise Vicki had low parenting confidence (C) and was worried about taking her baby into any social situation because she expected to be judged adversely on her parenting skills (M): "I was afraid that he would start screaming, and that everybody would hate me, and that I would panic when he was crying and I couldn't stop him."

The separation of peer support from the normal social circle was seen by some as important to maintain confidentiality (M): *"I walk in trusting them that it is confidential, and I can literally spill my* 

*heart"* (Brooke). On the other hand, a couple of mothers had attended the peer support with a friend or taken it up following a friend's recommendation, suggesting the absence of this mechanism. In addition, peer supporters with young children might not be wholly separated from the mother's social circle: *"The other thing 'peer' means to me, these are people that I go to baby groups with, or we're on the same WhatsApp mums' group"* (Rachel(V)).

# 8.2.1.6 Mechanisms: looking for normalisation and hope

Some mothers said that they were looking to support from peers to help them find an appropriate reference group for social comparison. They felt that this would help them reduce their feelings of abnormality and separation (M): *"Know I'm not the only one, talk to others who I identify with and who can relate, put perspective on how I feel"* (CW39). This hope inspired Hema to attend a peer support group, but she also had misgivings about whether the others would really be peers who could give this validation: *"Something I was scared of, thinking, 'What if I'm just <u>extra</u> crazy and <i>they've not got all of these things that they're feeling?"* This underlines the importance of a mother's beliefs about the specific meaning of 'peer experience' in her decision to take up an offer of peer support.

A few mothers had identified a need to meet someone who had recovered from perinatal mental health difficulties, in order to gain or sustain their own hope for recovery (M). For Annie, this had motivated her to overcome her initial cynicism about peer support: "*I was a bit negative, thinking, 'It's probably going to be the same [as therapy]. They'll tell me to use the same techniques, and I'll try it and it won't work."* [But once I knew] it was mums that had been through something similar themselves ... I thought, that'd be quite nice, speaking to a mum that feels better now and can be like, 'Don't worry, you've got this. I'm okay now, I've got this.'"

# 8.2.1.7 Mechanism: wanting to learn from experiential knowledge

Many of the open text comments referred to mothers' beliefs that they would be able to learn coping strategies (M) from other mothers to manage feelings of anxiety, depression, anger, and intrusive thoughts. This mechanism was also present in some interviews, but was much less prominent than the mechanisms discussed in sections 8.2.1.5 and 8.2.1.6.

"I wanted to be able to talk to [the volunteers] about what strategies do they find to be helpful, and just pick up tips off them." (Natalie)

# 8.2.2 Social connection

There were other reasons apart from mental health for mothers to feel cut off from others. A few said that they had very little social support at any time (C): *"I've never been able to talk to people, so I don't really have any friends or family"* (Morgan). For some, social isolation had been caused by a

recent move to a new town or to the UK during pregnancy (C): "[I felt] like I didn't belong here, I felt out of place in my local community because I didn't know it yet" (Wendy). Others were isolated because they were the first in their social circle to have a baby, for example Vicki described the disappointing experience of trying to meet her needs for social support by befriending other new parents (C) : "The people that you want to talk about it with aren't talking about it...We had to make a whole bunch of new friends, and you feel like you're spending a lot of time with people that you know you wouldn't spend time with apart from the fact that they're parents and you're parents."

Social isolation had prompted some mothers to look to peer support to fill this gap. In open text comments, mothers who described themselves as isolated referred to a general need for social connection and friendship through attending a group, as well as the desire for this to come from peers (M): *"Feel quite alone, especially since baby no.2. Family seem to be losing patience and I don't know many other people I can talk to."* (CW51)

This mechanism was not necessarily present for mothers who had a strong social network: "I didn't really want to make friends, I didn't want to bond with anybody" (Hema). Oona observed that women with social anxiety might be actively deterred by the invitation to social connection through peer support: "It's not going to be everyone's cup of tea. In terms of that social aspect, if that's what they're struggling with anyway, it probably wouldn't be the best idea."

### 8.2.3 Structuring time and space

For some mothers, the initial attraction of the peer support was not necessarily related to the peers but to the structure that a regular group offered (M) in the context of the chaotic early months with a baby (C): *"It gives me a routine. I like routines"* (Paige). It gave them a reason to get out and a place to go (M): *"I just wanted to reason to leave the house once a week, even if everything else was crap"* (Erin).

# 8.3 Peer support and professional support

As described in section 7.4.4.5, two-thirds of mothers who used peer support had been referred by a professional. There were complex relationships between mothers' decision to use of Parents in Mind and their experiences of health professional support.

### 8.3.1 **Primary care professionals as referrers**

A few mothers reported a helpful response from health professionals to their disclosure of perinatal mental health difficulties (C): "My midwife was so lovely, calm, and understanding... 'Let's get you

sorted, you're not on your own'" (Brooke). A few had implicitly trusted their health professional's recommendation to try peer support (M): "The service is because her midwife thinks it will help her. She's not sure what to expect out of the service" (N29: written by local project manager on her behalf).

Others said that health professionals' lack of time and understanding (C) had blocked their attempts to get help. Some had tried to talk to primary healthcare professionals, but were disappointed in the non-empathetic response that minimised their feelings and missed opportunities to refer: *"The health visitor wasn't [on] quite the same wavelength as me ... She come across as a bit condescending. She said, 'You know, with one of my children I was teary'"* (Cora). Several described experiences of busy health professionals not paying attention: *"They'll ask the question ... but they really just want you to say you're alright ... All of [the midwives] are too busy to really listen"* (Vicki).

Some mothers reported that even if they managed to communicate their distress, health professionals had not referred them to the peer support available, apparently unaware of its existence or utility (C): *"I was asking if there's anything else that I could do locally or if there was anyone I could speak to. [The doctor] told me there was nothing I could do"* (Oona). Several said they had been given information about Parents in Mind only as an afterthought: *"When I went in and said 'I need help, I can't do this; I'm terrified', they weren't sure as to what they could do, other than put me on a counselling waiting list. And then as I'd finished my breakdown and we'd stood up, we spotted the Parents in Mind leaflet on the windowsill, and it was like, 'Oh, what about this? Ring these'"* (Sal). It is possible that professional referrers at site 1 may also have been confused by the existence of several third sector organisations in the area offering support for perinatal mental health difficulties, one of which had a similar name (Mums in Mind).

Natalie's experience is quoted at length to illustrate the persistence she needed to get any help, including eventually a referral to peer support, and her reliance on health professionals to advise her on the mental health support available (M):

"[The locum GP] said, 'Come back in three weeks and we'll see how you're doing. In the meantime, here's a self-referral card for some therapy.' As soon as I got home, I picked up the card and it was for teenagers, I obviously wasn't eligible to use that... Within two weeks, I was worse again. I saw my own GP. I told her categorically how suicidal I felt. I remember her reaction being quite sympathetic, but she said, 'You're on the waiting list, there's actually nothing more I can do.' ...I then went to a health visitor... I had to sit down and tell this health visitor [everything] in a weight clinic. There was no offer of having a private conversation with her. I sat there crying with other women around me with their babies, and she said my health visitor had left, and in two weeks they'd deal with me...I said that I knew I was dangerously ill and that somebody needed to help me... Later that afternoon, I got a phone call from my health visitor - the new one - saying she wanted to come and do a home appointment with me. She was the one that gave me [Parents in Mind]'s number. It was really flipping hard. I was at the point of making suicide plans."

A few mothers mentioned that direct self-referral to peer support (M) had offered a way to bypass a potentially humiliating encounter with a health professional to ask for help with their mental health (C): *"It's that whole feeling of being judged and I was feeling quite proud, and I didn't want to feel embarrassed having to go back to the doctors and go through that process"* (Hema).

### 8.3.2 **Peer support offered instead of, before or after professional support**

Some mothers were referred Parents in Mind after they applied for professional mental health support. This might be in lieu of psychological support if they had been professionally assessed and turned down as not meeting the service criteria (C) but believed peer support might help them instead (M): *"I was originally referred to IAPT, but IAPT said they wasn't able to deal with pregnant women, and they passed me to Parents in Mind"* (Julie). In a small number of open text comments, peer support was a 'step down' service after professional mental health support ended (C), which mothers hoped would help with the adjustment (M): *"Leaving the perinatal mental health team to the community team and think this group will be helpful during that transition"* (CW106).

Alternatively a mother might be referred to peer support as a solution to long waiting lists before therapy started (C), by health professionals who did not necessarily understand its distinctive contribution: *"I think they're seeing us like a holding group: 'Here's somewhere where you can go to be supported while you're waiting for support"* (LPM, site 3). This option could be welcomed by a mother who was desperate (M). For example, Natalie believed that peer support could help her to cope while she was on a waiting list for the therapy which she hoped would help her to recover from her mental health difficulties: *"I wanted it to be some sort of stop gap...I didn't have any thoughts that it would be a cure, but I thought it would potentially tide me over or help me not to deteriorate"*. At site 2, the local project manager had observed that immediate support was a strong selling point for peer support (M): *"Particularly if they're waiting for CBT or other interventions to start, I can see that surprise and happiness that there's support being offered immediately."* This mechanism may have been influenced by the timing of the evaluation within the pilot of a new peer support intervention which had not yet become widely embedded with local referrers, so there was plenty of capacity.

### 8.3.3 **Peer support in tandem with professional support**

Several mothers had decided to take up peer support at the same time as psychological therapy (C), in the belief that it offered something different from professional support or was a part of their strategy to try anything that was available (M): *"I applied for Parents in Mind. I also applied for Coventry Mind, the Recovery Partnership just in case it was to do with detox ... Just trying to find someone to help me find a way through"* (Brooke). By contrast, one mother said she had heard about Parents in Mind from a friend who had chosen <u>not</u> to use peer support because she was already receiving professional support: *"Her psychologist from the mental health team at the hospital had spoken about Parents in Mind ... Because she was having one-to-one support at that point she didn't use it."* (Di)

# 8.3.4 **Peer support as a chosen alternative to professional support**

Some mothers had self-referred to peer support while making a deliberate choice not to seek professional help. This might be because they did not feel their symptoms were serious enough for professional support (C): *"I identified I needed to do something, but I didn't know what, because I'm not at a level of needing to be referred to a service"* (Flo). By contrast to Natalie quoted above in section 8.3.2, open text comments indicated that some mothers believed peer support could be a solution to their mental health difficulties (M), independently of professional support, particularly if their difficulties were mild: *"Hope to feel less anxious and depressed"* (CW113).

Others actively wanted to avoid professional mental health support (M) because of disappointing previous experiences, where professional support had not helped: *"I had counselling but it was not great … some of the things she said, it made me feel worse"* (Lena); or they had felt judged (C): *"I don't really talk to many people, like counselling; I won't talk to my social worker because my social workers have judged me, and it's made me feel as if a lot of this is my fault"* (Morgan).

Some volunteers and local project managers suggested that the informality of peer support might be attractive to mothers with negative experiences of professional therapy (C): *"We work well with people who have been let down by services. Because we're in the third sector, it occupies a different thing – it's worth a try if there's a lack of trust with professionals"* (LPM site 3). Across different cultures, volunteers suggested that informal peer support might feel 'safe' (M) to mothers who were apprehensive that disclosing mental health difficulties to professionals would lead to a safeguarding intervention from social services (C):

"We have the rumour that if you are mental ill, in my society they say, 'If you mention this to a professional, your children will be taken away.'... But if it's just a [volunteer] who you meet and it's

not written or any paper filling, you just talk and friendly, I find that this give everyone the confidence to speak to the stranger." (Black African volunteer)

"Going to see someone that hasn't experienced postnatal depression ... you feel like they're going to phone social services, like they're going to take your children away... I would feel a lot safer seeing someone who has been through it." (White British volunteer)

Alternatively some mothers who had a successful past experience of psychological therapy (C) chose to use peer support because they saw it as offering something valuable in a different way (M): "I've done a few lots of person-centred therapy. I have been over and over all of the bad stuff that's happened in my past, I don't feel I need to keep doing that. So I wanted to learn new ways to deal with my emotions ... and work out strategies" (Oona).

# 8.3.5 **Peer support as an accidental choice**

Finally, there were mothers for whom the 'peer' aspect was not an initial motivating factor, as they did not understand that the support was from peers: "*I didn't realise it was with other mums until I got there … I just needed somebody to speak to*" (Sal). Some had assumed that what was offered would be similar (M) to the professional support which they wanted (C): *"I thought it would have more of a counselling session than it actually is*" (CW17). The local project managers observed that these mothers quickly stopped using peer support when they realised it was different: *"I thought I had explained Parents in Mind really well, but after [the mother] met with a volunteer who 'just' had lived experience, she said she felt it was not for her … She has had her quota of talking therapy but she still needs more strategies to help her manage her mental health and she didn't feel the peer support could give that" (LPM site 3).* 

# 8.4 Format of support

## 8.4.1 **Daytime face-to-face support in a public place**

Parents in Mind groups were only offered during the day, limiting some mothers' access (particularly pregnant women who were working) (C). The restriction on volunteers going into a mother's home or giving support by telephone excluded mothers who were not able to travel to a meeting, for example because of disability, agoraphobia, or at crucial periods in late pregnancy or recovering from birth (C). Mothers' need for peer support might be most acute at times when they were least able to keep an appointment: *"We can't say we're an inclusive service if a woman who's just had a c*-

*section can't get any support from us because she can't drive"* (LPM site 1). This was also problematic if there was no safe indoor space locally in which the volunteer and mother could meet (C).

Local project managers saw the use of telephones as a way to overcome these logistical barriers (M) (the opposition to introducing telephones is discussed in section 7.5.7):

"In the deepest darkest November, when you've got a four day old baby and you've been up all night, and you can't get yourself out to a children's centre – that could be a phone call. It's the reality of being there for these women when they actually need us." (LPM, site 2)

### 8.4.2 **Choice of one-to-one or group support**

Both one-to-one and group peer support were available through Parents in Mind, and efforts were made to reassure mothers that the groups were relaxed and informal: *"You can come when you want, leave when you feel ready to leave, there's not a structure. This takes the pressure off thinking it's women sitting in a circle like it's AA [Alcoholics Anonymous]"* (LPM site 2). However, at sites 2 and 3 several mothers referred to the difficulty of attending a peer support group when they had social anxiety (C) – Morgan said this prospect was *"terrifying"*. For these mothers, having the option to have one-to-one support was essential to give them the confidence to use peer support (M). By contrast, a couple of mothers said in open text comments that they specifically wanted to attend a group in order to build their social confidence (M), for example: *"To gain in confidence and feel calmer in a group situation"* (WR017).

Others were intimidated by the prospect of a one-to-one meeting about their mental health, suggesting they would also avoid one-to-one support (M). At sites 2 and 3 in particular, many mothers repeatedly cancelled the referral meetings or did not turn up: *"One lady took four meetings before I actually got her"* (LPM site 2). Vicki described how the referral meeting had been a barrier that nearly led to her not using the peer support; she would have preferred the informality of a drop-in group:

"I definitely thought about not going, because I would have to sit in a one-to-one situation with someone and I was scared. ... If it's just you and another person and you're coming in to talk about <u>you</u>, and there's going to be a form that you have to fill in about <u>you</u>, there's nowhere to hide. And so if you're not feeling brave that day, you might cancel and then you might feel like you couldn't ask to go again because you feel like you'd let everyone down because you'd cancelled."

# 8.5 Cultural issues

Parents in Mind was much less successful than had been hoped in reaching mothers from Black, Asian and other minority ethnic backgrounds. Mothers from these backgrounds who *did* take up support gave reasons identical to those given by White mothers, as illustrated in the following examples of open text answers:

"To learn from other people's experiences. Platform to have an open discussion about how I feel" (CW23, British Asian)

*"Tips/support to help cope with anxiety and with managing 4 kids under 4 years old."* (N29, Black British)

"Would like to feel like I'm not alone with my issues and alleviate feelings of guilt" (CW85, Black Caribbean)

"A safe space where people understand how I'm feeling. To make me get out of the house and attend the group" (N10, Black African)

At site 3, the volunteers at site 3 reflected the local ethnic and linguistic diversity, and leaflets advertising the programme featured an Asian mother wearing a hijab. These efforts to make Parents in Mind attractive to mothers from all communities proved unsuccessful (see section 7.4.4.2). The insights of staff and volunteers about cultural context, and how this might inhibit mechanisms leading to uptake, are presented in the following subsections.

### 8.5.1 **Rejection of 'mental illness' and talking about emotional distress**

# 8.5.1.1 Mothers' own concepts

Although the local publicity materials avoided any mention of 'mental illness', the concept of seeking support for any emotional distress through talking may not be accepted by some mothers (C): *"Unfortunately we do come from a culture where emotions aren't spoken about like that"* (British Bangladeshi volunteer). They might be unable to admit their distress even to themselves if their religious culture did not legitimise their feelings (C):

"Coming from an Asian background, I think that depression is not recognised. People think that you don't get depressed if you're Muslim, if you have faith in God ... If you <u>are</u> feeling depressed you don't always recognise it in yourself, so how can you go and seek help?" (British Pakistani volunteer)

Several volunteers acknowledged that the stigma of mental illness was a cross-cultural phenomenon, although the forms it takes might be specific to a culture: *"What I've learnt is most of the cultures are pretty much the same, because there's the stigma of mental health in every culture, and everybody is* 

pretty much told to stop it" (British Bangladeshi volunteer). As described in section 8.2.1, internalised stigma was a pervasive experience for the mothers interviewed, almost all of whom were White British, and some of whom also linked this stigma to their own cultural background: *"I think it's just the British culture just to pretend like everything's fine"* (Natalie).

### 8.5.1.2 Family gatekeepers

Even if a mother herself recognised that her distress was something she could legitimately seek help for, this might be obstructed by family gatekeepers (C): *"If the family know that you're going because of mental health, it would be like, 'Why should you be?' I think mainly it is the family that prevents women going out and seeking help"* (British Bangladeshi volunteer).

One mother who accessed Parents in Mind against her husband's opposition managed to do so secretly, by meeting a volunteer at a community centre without her husband's knowledge: *"She is 'not allowed' to get support: her husband said 'You don't have a mental health issue, you have a moral issue'"* (LPM site 3). This illustrates both the contextual barrier and how it could be overcome if a mother who strongly wanted peer support was prepared to take the risk.

# 8.5.1.3 *Preference for practical support*

For communities with a tradition of helping each other through practical support rather than talking about emotions (C), peer support based on listening may be less attractive than a group based around an activity (M): *"The training was so geared towards White, middle class women: 'sit face-to-face and talk'...It would be good to combine it with other activities because for many cultures that face-to-face does not work"* (trainer, site 3).

Where a mother did not acknowledge her own distress or was not permitted to speak about it, it might be culturally acceptable for her to seek help for a physical issue (such as breastfeeding) (M). This was the rationale for attaching Parents in Mind volunteers to a breastfeeding drop-in group at site 3, where they could talk to mothers opportunistically: *"It's clear this mum wants to see a [mental health] peer supporter but she doesn't want people to know that; she will see one of our dual-qualified peer supporters who will tell her 'Let's breastfeed in the other room'. So she has the safety there that she will outwardly see a breastfeeding peer supporter but she is getting mental health peer support" (trainer, site 3).* 

This was also one reason for the change to a drop-in mother-and-baby group at site 3. The advertising for this group emphasised maternal emotional wellbeing: *"This is a friendly space for pregnant or new mums with babies up to 2 years who are feeling low, anxious and alone"* (Parents in

Mind Facebook post). Nonetheless staff and volunteers believed that the positioning as a 'Bumps and Babies' group, available without an initial referral process, made it accessible to women without them having to identify themselves as seeking mental health support: *"The baby group I think really helps, because it's not outright, 'I'm going to a mental health group' ... it can be just because you're going for your baby to play"* (British Bangladeshi volunteer). As these innovations took place near the end of the pilot, it was not possible to evaluate whether they did indeed meet the aim of increasing access to peer support. However, one volunteer described how even these activities were not acceptable in her community, because attending any group would imply a motherhood deficit: *"The problem is we have the belief that you're a woman, you know what to do. You get married, you have a child, so everything should come naturally ... in any group you will find very less of our people, very, very less"* (Black African volunteer).

# 8.5.2 Shared cultural background

## 8.5.2.1 *Fears about confidentiality*

Peer support was not necessarily seen by mothers as a way of achieving confidential support in a densely networked community (C), and the risk of meeting peers from the same background at a group could be an obstacle to uptake (M): *"Women do not want to be seen by other women in their same community talking about an issue like this, because they feel embarrassed"* (British Bangladeshi volunteer). Contrary to staff expectations, some mothers from ethnic minority communities did not even want one-to-one peer support from a volunteer with a shared cultural background:

"[Mothers] would meet me and it was a really good session, but they wouldn't go any further – they would cancel before the [volunteer] ... If you're from the same culture, many of them feel that you can train them to be non-judgmental as much as you want, but it's cultural, you can't take it out of them." (LPM, site 3)

# 8.5.2.2 Desire for cultural or linguistic similarity

There were also a few examples of the opposite mechanism, where a shared cultural or language background had motivated a mother to take up peer support (M) because they felt that would enable real understanding (C): *"There's an Asian lady who has come for the past three weeks, but she initially only came because she wanted to see a Muslim mother"* (British Indian volunteer). Another mother wanted mother-tongue support from someone who would understand the culture shock she experienced on moving to the multi-cultural borough: *"Feel more comfortable to live here and not be in shock of the diversity of people everywhere, need support from a mum who understands the pregnancy journey that speaks Russian"* (N14). The local project manager at site 3 took a cautious

approach to matching mothers with volunteers for one-to-one support, noting that in practice culture was only one factor in a successful match: *"I wouldn't put them together just because they had the same religion or experiences, if their personalities are not right"*.

# 8.5.3 Accessibility

Women with domestic responsibilities in extended families (C) might not be able to leave the house to spend time on their own wellbeing (M). In addition, although there was the option of mother-tongue support in a range of languages at site 3, the referral process (which required initial contact with the local project manager) could be a barrier for a mother who did not speak any English (C): *"I think sometimes making that phone call is maybe too much for anybody, but obviously if you don't have the language, you're not going to make that phone call"* (British Bangladeshi volunteer).

# 8.5.4 **Personal invitation**

Several volunteers suggested that, given the unfamiliarity of the concept of peer support, what was needed in their community was an explanation or direct invitation from a trusted intermediary. They believed that this would be more effective than advertising and felt that they could have a role as ambassadors for the programme: *"If you speak to people and explain what it is that you're doing, they're much more willing to hear you, and maybe, because they can put a face to it, they then are thinking, 'OK'. It's about trust, isn't it?"* (British Bangladeshi volunteer). However, the overall experience of volunteers giving 'floating support' in other groups, which did not translate into take-up of Parents in Mind support, suggested that this was not in practice sufficient to overcome other obstacles. It may be that an invitation from a trusted community leader would be more effective.

# 8.6 Social circumstances

# 8.6.1 **Practical issues**

Many of the disadvantaged mothers in the borough at site 3 were in temporary accommodation and had to move on at short notice (C), so were only able to use peer support briefly or did not think it worthwhile using it at all (M). The large size of the borough created opportunities with more eligible mothers in the catchment area, but also posed logistical and financial difficulties in terms of public transport (C). The cost and logistics of public transport (C) also affected mothers in the other sites, because of the large rural area in site 1 and the poor transport links between Widnes and Runcorn at site 2: *"I haven't been able to come much recently due to transport but helpful to know there is someone there to talk to"* (CW15). The fact that mothers who were single parents or had other

children were less likely to take up peer support when referred (section 7.4.4.2) suggests that childcare responsibilities may have also limited some mothers' access.

# 8.6.2 Severe and multiple disadvantage

Some of the mothers referred at site 3 faced complex issues of immigration status, homelessness, social security entitlement and domestic abuse (C). It had been hoped to reach some of these severely or multiply disadvantaged mothers by working in partnership with the Magpie Project, a charity supporting homeless mothers, but this was not successful. These mothers were not able to prioritise their own wellbeing and did not have the material and psychological resources to make use of the peer support (M): *"A lot of our complex women don't have time to be coming out to things, so they want one service not three services, or they've got three kids or they're coming too far"* (LPM site 3). In addition, as some mothers' perinatal mental health difficulties were inextricably embedded in their situations of severe or multiple disadvantages, the local project manager felt that their needs would be better served through a more holistic programme such as Birth and Beyond Community Supporters (BBCS), which allowed peer supports: *"I would like them to give practical support and to support in a woman's own home, it should basically be BBCS volunteers with training around mental health"* (LPM site 3).

A further barrier was that access to Parents in Mind required the filling out of forms with personal details and an informal mental health assessment. Contrary to volunteers' hopes about the relative safety of peer support (quoted in section 8.3.4), this level of formality and self-disclosure could feel unsafe (M) to mothers who feared the involvement of social services (C):

"The last woman said, 'You can say it's confidential, but I've just been through the court case where they've taken my three children, and the therapist said the same, but it <u>was</u> used'. And what can you say to her?" (LPM site 3)

By contrast, several mothers at sites 1 and 2 who took up support (or wanted to) <u>were</u> experiencing severe or multiple disadvantages, particularly connected to poverty and domestic abuse – for example Morgan, whose situation was quoted in section 8.2.1.1. If they were already working with social services (C), using peer support did not create an additional concern about disclosure and they could trust its confidentiality (M).

# 8.7 Comparison between initial theory of change and final theory of change for take-up

The 16 context-mechanism configurations identified during the primary research, where the outcome was take-up of peer support, form part of the final theory of change for Parents in Mind. In Table 20, these context-mechanism configurations are compared with those hypothesised in the initial draft theory of change.

# Table 20 Comparison between initial and final theory of change for take-up

Context		Mechanism		Initial	Final
Social level	Individual level	Resources provided by peer support programme	Reasoning or reaction leading to use of peer support	theory of change	theory of change
Cultural narratives of idealised motherhood.	Negative self-labelling as a uniquely abnormal 'bad' mother	Offer of peer support	Mother <u>believes</u> peers will be empathetically understanding and trustworthy	1	1
Stigma of mental illness. Expectation that new mothers will	Hides feelings from partner, family & friends & can't meet needs for authenticity in relationships	Offer of peer support	Mother <u>believes</u> peers will make her feel normal	1	1
meet social support needs through other new parents	Avoids new parent groups as these make her feel worse	Offer of peer support	Mother feels safe to attend because peers are outside normal social circle	1	
		Offer of peer support	Mother feels safe to attend because <u>believes</u> peers will be non-judgementally accepting	1	1
Public health campaigns promote message 'it's good to talk', but there are differences in acceptability of talking to outsiders	Mother believes it is useful and acceptable to talk about mental health difficulties	Offer of peer support	Mother wants to talk about her mental health	1	1
	Worries she may never recover	Offer of peer support	Mother <u>believes</u> peers will give her hope of recovery	x	1
	Life with a baby feels chaotic and lacks structure	Offer of peer support	Mother <u>believes</u> regular peer support will help to structure her time and give her a reason to leave the house	x	1
Pressures resulting in forced migration; rehousing policy following domestic abuse	Mother is socially isolated / first in her circle to have a baby	Offer of peer support	Mother <u>believes</u> peer support will provide friendship	×	~
	Mother has mild perinatal mental health difficulties	Offer of peer support	Mother <u>believes</u> peer support will help her recover	x	1
Primary health professionals have limited training on perinatal mental health difficulties and limited time and limited awareness of peer support	Conceals symptoms from professionals – fear of judgment, consequences, lack of understanding Disappointing experience of professional support	Peer support is available by self-referral	Mother <u>believes</u> peer support is a safe or better alternative, or trusts lived experience over professional knowledge <i>for advice on</i> <i>coping and self-care</i>	1	1

Context		Mechanism		Initial	Final
Social level	Individual level	Resources provided by peer support programme	Reasoning or reaction leading to use of peer support	theory of change	theory of change
Primary health professionals have limited training on perinatal mental health difficulties and limited time	Mother trusts health professionals	Programme has good relationship with local health professionals and a simple referral process	Mother is referred by a health professional she trusts	1	1
Different conceptions of mental health difficulties and appropriate response	Personal conception of cause and meaning of perinatal mental health difficulties	Programme terminology matches mother's own understanding of her mental health	Mother believes that the peer support is aimed at people like her	1	x
	Mother has preference for cultural homogeneity or heterogeneity	Programme is able to offer a choice in cultural matching or otherwise	Mother feels safe to attend because similarity or difference matches her needs	1	1
Limited access to perinatal mental health support, including long waiting lists	Mother wants counselling	Programme positions self as alternative for those who do not meet criteria for professional support	Mother may go to peer support as a holding position while waiting for counselling or hoping she will receive counselling-type support or as step down from psychological therapy	<i>✓</i>	
Social norm that mother is primarily responsible for meeting baby's needs alongside domestic responsibilities and other work	Mother has resources of time and/or money to invest in meeting her own needs	Programme offers support requiring less commitment e.g. by phone or drop in group	Mother can use peer support in ways that do not exceed her resources	1	
Cultural norm that positions family members as gatekeepers to woman's access to activities outside home	Mother has autonomy to make own decision about attending	<i>Offer of peer support (potentially camouflaged by another activity)</i>	Mother able to make her own decision to attend	x	
	Low social confidence	Programme offers choice of 1:1 or group support	Mother feels safe talking to a peer supporter 1:1 although would not feel safe in peer support group, or vice versa	1	1

# Кеу

*Italics:* New contexts and mechanisms that were in the final but not the initial theory of change Strikethrough: Contexts and mechanisms that were in the initial but not the final theory of change

# 8.8 Chapter summary

This chapter has explored the varied contexts and mechanisms involved in mothers' decisions about taking up Parents in Mind peer support, in order to answer research questions 2 (take-up) and 5 (group or one-to-one). A mother's decision could be affected by social attitudes to motherhood and mental health; health professionals' skills, understanding and time; the organisation of perinatal mental health services; the severity of her mental health difficulties; and other issues connected to her personal situation or background. These contextual factors triggered a wide range of mechanisms leading to the outcome of taking up peer support, primarily grounded in mothers' beliefs about what peer support would offer them. There were also situations where contextual factors related to beliefs, culture or socio-economic disadvantage might override these mechanisms or cause them not to activate. The next chapter explores the positive and negative contexts, mechanisms and outcomes for those mothers who took up the perinatal mental health peer support, to answer research questions 3 (the change model for mothers) and 5 (group or one-to-one).

# 9 Parents in Mind Study - Results, Part 3 (Impact on Mothers)

# **Chapter overview**

This chapter presents the third part of the results of the primary research, answering research questions 3 (the change model for supported mothers) and 5 (the differences between peer support in a group or one-to-one). This chapter begins with an overview of the final theory of change related to impact on mothers. It reports the changes in mental health scores during mothers' use of peer support, and mothers' attributions of impact and alternative explanations for these changes. It then examines the complex ways in which peer support interactions generated mechanisms in different contexts leading to varied psycho-social outcomes.

# 9.1 Theory of change for the impact of peer support on mothers: introduction

An overview of the final theory of change related to the impact of peer support on mothers is shown in Figure 8 and Figure 9, followed by a narrative description of these theories and the evidence used to derive them. To avoid repetition from earlier chapters and to reflect the emphasis given by interviewees, only individual contextual factors are described here; however it must be remembered that these individual factors arise within a wider social context, described in detail in the realist review.

Although all of the mothers were very positive about their peer support experiences, participants also identified ways in which peer support could sometimes make a mother feel worse (although all believed the positives far outweighed the negatives). These unintended consequences were usually generated by the same, or closely-related, peer support activities as the positive outcomes, so in the narrative sections they are presented together. For clarity they have been separated in the two figures below: Figure 8 shows the positive theories, and Figure 9 shows the 'dark logic' of unintended consequences.

Mechanisms are shown in two parts: the resources offered (i.e. what happened during peer support), and mothers' reasoning or reaction to these resources. Peer support was not a singular resource but a series of interlocking activities, which were not necessarily all present in any individual encounter. The activities depended on the needs and personality of the mother(s); on the skills, confidence, personality, training and experience of the volunteer(s); on whether the support was horizontal (between currently unwell mothers at a group) or asymmetrical (between a volunteer and a mother); and whether the support took place in a group or one-to-one.

### Figure 8 Positive context-mechanism-outcome configurations for mothers



### Figure 9 Negative context-mechanism-outcome configurations for mothers



# 9.2 Mental health outcomes: HADS scores and attributions of impact

# 9.2.1 Hospital Anxiety and Depression Scale data

This section presents the results of the self-report questionnaires which were used to track mothers' mental health during their time using peer support. There was at least one follow-up assessment available for 57% of mothers who were supported (n=103). Two-thirds of mothers had lower anxiety (66%) and depression (68%) scores after peer support as measured by the Hospital Anxiety and Depression Scale (HADS), and one third of mothers had higher (22%) or unchanged (anxiety 12%, depression 10%) scores. The range of change was also very wide: +8 to -14 points for anxiety scores, and +8 to -15 points for depression scores.

Table 21 shows the changes in median Hospital Anxiety and Depression Scale (HADS) scores between baseline and the last assessment. There were statistically significant reductions in both anxiety scores (Z= 5.59, p=0.000) and depression scores (Z= 4.99, p=0.000). Median anxiety scores reduced from moderate to mild, and median depression scores reduced from mild to normal.

	Median	Range	Inter-quartile range
Baseline anxiety score	13	2 to 20	6
Anxiety score at latest follow up	10	0 to 21	7
Change in anxiety scores	Z= 5.586 (p=0.000)		
	Г	[	
Baseline depression score	9	0 to 20	5
Depression score at latest follow up	5	0 to 20	8
Change in depression scores	Z= 4.985 (p=0.000)		

**Table 21** Change in Hospital Anxiety and Depression Scale scores during use of peer support

Mothers' own perceptions of causal links between peer support and changes in mood are explored in the next two sections, addressing mothers' attributions of impact and alterative explanations.

# 9.2.2 Attributions of impact on mental health

# 9.2.2.1 Attributions: quantitative data

The follow-up questionnaires asked mothers to rate ways in which Parents in Mind had helped them (covering both mechanisms and outcomes), and response data were available for 96 mothers (53% of

those supported), whose answers are shown in Table 22. They also had the option to answer 'not applicable', indicating that this was not something that they wanted help with.

The highest ratings for mothers answering that Parents in Mind had helped them 'a lot' or 'quite a lot' were for feeling there was someone to talk to who understands (although it was notable that 10% of mothers experienced this core peer support mechanism only 'a little bit'); feeling less isolated and alone; and knowing where to get help if needed. Most agreed that peer support had helped them feel more positive, but a quarter said this was only 'a little bit' or 'not at all'.

Answers to the question 'Parents in Mind has helped me to' (n=96)						
	A lot	Quite a lot	A little bit	Not at all	Not applicable	
Feel there is someone I can talk to who understands me	61 (63%)	24 (25%)	10 (10%)	0	2 (2%)	
Find ways of coping when I'm feeling down	38 (39%)	23 (24%)	28 (29%)	2 (2%)	6 (6%)	
Feel less isolated and alone	57 (59%)	27 (28%)	12 (12%)	0	1 (1%)	
Feel more hopeful about the future	46 (47%)	25 (26%)	21 (22%)	1 (1%)	4 (4%)	
Know where to get help if I need it	61 (63%)	23 (24%)	7 (7%)	1 (1%)	5 (5%)	
Access the services I need	50 (52%)	27 (28%)	13 (13%)	1 (1%)	6 (6%)	
Generally feel more positive	44 (45%)	27 (28%)	22 (23%)	1 (1%)	3 (3%)	

### Table 22 Follow-up questionnaire answers on attribution of impact

# 9.2.2.2 Attributions: qualitative data

In the open text answers and in interviews, many mothers stated explicitly that they believed the peer support itself was responsible for their improved mood (O): *"I've found the group to be a lifeline …. It's definitely helped me feel less anxious"* (Grace). Although Natalie only expected peer support to help her cope while waiting for therapy (see section 8.3.2), she believed that it had in fact helped her mental health directly: *"I did actually see some improvement, which I wasn't expecting … I feel very lucky that I'm in an area where [peer support] is a possibility because quite frankly, I wouldn't have been here if something hadn't changed."* 

Looking back on the first two years of the pilot, the peer support team leader distinguished between how peer support appeared to directly reduce anxiety and depression (O) for women with milder,

transient mental health difficulties (C), but might have a different function (O) for mothers who were more seriously unwell (C):

"The low-to-moderate people, who just feel like they need to go somewhere for a few months where they can be honest and real, absolutely I think that peer support can get them out of that spot. But the moderate-to-severe people, you're talking about people with issues that will probably never be 100% free of them."

This perception was borne out by three mothers for whom there were substantial <u>increases</u> of 8 points in HADS anxiety or depression scores during the time they received peer support. These mothers all had significant long-term mental health difficulties, and were current or recent clients of the perinatal mental health team. All three commented in open text that Parents in Mind had helped them to cope with their mental health difficulties (O) and feel better than they would otherwise, even if overall their mental health had declined: *"The group and one-to-one has been so incredibly helpful"*(CW102).

# 9.2.3 Alternative explanations for changes in mood

# 9.2.3.1 Alternatives: quantitative data

Mothers were also asked in baseline questionnaires whether they were taking any medication for their mental health or receiving any psychological therapy, and if so, whether it was helping them to feel better. These interventions could provide an alternative explanation for any changes in mood during the period that they were receiving peer support.

49 mothers (27% of those who took up peer support) answered 'yes' to the question 'Are you taking any medication for your mental health at the moment?' Of these, 39 (80%) answered 'yes' to the follow up question, 'Do you feel it is helping you feel better?' This suggests that medication could have been responsible for improved mood in 21% of mothers who took up peer support.

34 mothers (19% of those who took up peer support) answered 'yes' to the question 'Are you having any counselling or therapy like CBT at the moment?' Of these, 32 (94%) answered 'yes' to the follow up question, 'Do you feel it is helping you feel better?'; the two who did not answer 'yes' both added the comment 'Too soon to tell'. This suggests that counselling or therapy could have been responsible for improved mood in 18% of mothers who took up peer support.

# 9.2.3.2 Alternatives: qualitative data

Some mothers explained in interviews that peer support was just one among a number of factors that had led to an improvement in their mood. Sometimes these were changes in their situation, such as

their baby starting to sleep better, resolution of physical health problems, or a return to work: "Going back to work helped, as much as going to the [peer support] group, because I had something to focus my time and my attention on" (Erin). Several said that the self-doubt of early motherhood had disappeared spontaneously over time: "Time makes things a little bit easier, and I suppose [my baby] is a little bit older, I've had more time to get used to being a parent" (Vicki). Interviewees who had used peer support alongside psychological therapy and medication usually attributed their improved mood (as reflected in HADS scores) to all of these:

*"I've really had some good support. My health visitor's started that road. The perinatal team, the doctor, and I've taken some medication, and then to counselling. Then obviously with Parents in Mind, I've had a lot of things to help."* (Cora)

Likewise some mothers chose to offer alternative explanations for why their HADS scores had <u>not</u> reduced while they were receiving peer support. Several said that they had started a psychological therapy which had stirred up difficult emotions: *"[Parents in Mind] has been a lifeline in offering me so much support. I am improving, but it's a slow process, and CBT has undermined that"* (WR05). Others mentioned dealing with new stresses from work, physical illness, family problems, or the stage of pregnancy. Some said that they had not been attending peer support regularly because they were overwhelmed with life challenges: *"My scores have gone up as I'm not having the best time at the moment. It's not a reflection on Parents in Mind because I haven't been for a while"* (CW33).

### 9.2.4 **Impact summary**

A complex picture of the impact of peer support on the symptoms of perinatal mental health difficulties emerges when integrating the quantitative and qualitative findings above. The majority of mothers' HADS scores reduced during their use of peer support, and the changes in anxiety and depression were statistically significant. Some mothers attributed these changes directly to the peer support, while others had alternative explanations. A third of mothers' HADS scores stayed the same or increased during their use of peer support; none of the mothers attributed these negative changes to the peer support, and some did give alternative explanations.

When mothers were asked by questionnaire about their attributions of impact, for most items (including 'generally feel more positive'), the percentage of mothers stating that Parents in Mind had helped them 'a lot' or 'quite a lot' was higher than the percentage of mothers whose HADS anxiety and depression scores reduced during their use of peer support. This suggests that peer support may have a role in

supporting and improving mothers' emotional wellbeing, or preventing it from deteriorating, even if specific symptoms captured by an anxiety and depression screening instrument are not affected. This was affirmed by the qualitative findings, and proximate outcomes are explored in greater depth below. There was some evidence that peer support was more likely to have an impact on anxiety and depression scores as measured by HADS ('recovery *from* mental health difficulties') for mothers with milder and more transient mental health difficulties, whereas an impact on subjective wellbeing ('recovery *within* mental health difficulties') was reported by mothers with more serious or entrenched difficulties.

### 9.3 Contexts, mechanisms and proximate outcomes

This section explores the programme theories related to the impact of peer support on mothers, mainly identified from the interviews with mothers and volunteers, and open text responses. Quotations are primarily from interviews, as the in-depth format enabled greater scope for identifying the links between contextual factors, mechanisms, and outcomes for mothers. These outcomes were mainly proximate psycho-social changes, which may have contributed to reduction in anxiety and depression for some mothers (see section 9.2 above), but which were also valued by mothers in their own right.

# 9.3.1 Being listened to and speaking openly

# 9.3.1.1 *Positive: Empathy, acceptance, confidentiality*

Active listening by the volunteers aimed to communicate their interest, understanding, and respect; and to enable mothers to open up about their feelings and feel heard: *"You relay what they've said to you, and you're saying, 'Yes, you found that really difficult? And how was it afterwards?'* ... That bottled emotion that they have is definitely offloaded on us, and then they do feel better about it" (Mel(V)).

Almost all the mothers interviewed described how peer support had indeed enabled them to talk freely about their true feelings (O), hidden from others (C) for the reasons discussed in section 8.2.1. Peer experience was believed to be an antidote to shocked or moralistic attitudes. Because peers could empathise, mothers felt understood (M), and because peers were not judgemental, mothers felt unconditionally accepted (M). Both empathetic understanding and non-judgemental acceptance were closely related to the experience of normalisation, discussed in section 9.3.3.1 below.

"There are some words that don't describe how you're feeling, but the other mums know what you're trying to say. It's like a mum code... If you've been through postnatal depression, I feel we've all got an understanding." (Paige)

"It's almost like a sigh of relief. You don't have to pretend, or you can explain the bad day you've had and you don't feel like anybody is judging you for making it worse than it sounds." (Grace)

Empathetic, non-judgemental listening was reinforced by confidentiality, independence from the mother's social circle, and the volunteers' absence of any agenda other than to offer support. This enabled mothers to feel safe to speak honestly, even about their darkest feelings of which they were most ashamed. Self-disclosure meeting unconditional acceptance had led to powerful experiences of emotional release (O): *"As soon as I walk out of there, I feel so much lighter, like the weight of that week has gone, and I feel so much happier… I can't describe the upliftment that she gives me"* (Sal). It also led to self-acceptance and improved self-esteem (O) and sometimes a new willingness to disclose feelings to family and friends (O):

"It's gave me a lot more confidence in myself. I used to go out feeling quite anxious and nervous, but now I'm able to go for walks with my son, and I'm not really feeling like anybody's watching me or judging me ...You just feel accepted. It's done a lot for my self-esteem as well." (Morgan)

"There were certain things that I could say to [the peer supporter] that I would feel guilty if I said to someone else ... It was such a weight lifted off my shoulders. She listens like it's okay not to be okay... She made me feel like speaking to my family about it, which made me feel confident do it." (Annie)

Like the staff quoted in section 7.5.2, volunteers had a mixed perception of how their lived experience might enable them to understand and connect with mothers. This is illustrated through three examples below, showing Izzy(V)'s belief in the importance of lived experience; Suzie(V)'s belief that mental health difficulties were too wide-ranging for a peer supporter to be able to empathise with all of them; and Tanya(V)'s belief that training was more important than specific mental health experience.

"You can have all the training in the world, you could go to universities and understand it amazingly, but unless you have that experience, you're not going to know how the mothers are feeling and you're not going to fully understand." (Izzy(V))

"There are women who have coping mechanisms [e.g. self-harm] that I cannot identify with at all, because that's not been part of my journey. I find that very hard to relate to, and I feel quite lost and a little bit out of my depth when I'm with those people." (Suzie(V))

"I think anybody could do some emotional support training, whether they have had poor mental health or not, because pretty much every mother who has had a baby has had some kind of strong emotion. I think that they can most certainly reach down, connect and empathise." (Tanya(V))

# 9.3.1.2 Negative: No opportunity to speak

Occasionally mothers did not get the chance to be heard, which thwarted the opportunity for emotional release and potentially led to disappointment (O). This might be because a less confident mother (C) did not feel able to join in when the conversation was dominated by more confident mothers (M), or because sometimes there was not enough time in a session for all the mothers to have a turn, particularly when the conversation was interrupted by needing to attend to the children.

"Sometimes, especially when we have six or seven people in the group, that didn't feel enough time to get around everybody... When you walk in and you think, 'I've really something to say,' and one week [another mother] walked in and just took over the whole conversation." (Brooke)

"I'd almost feel like it wasn't worth going sometimes, because if you're punctuating your conversation with changing nappies and chasing a toddler ... sometimes I'd have gone, and wouldn't have actually said anything, and then have had to go." (Erin)

Volunteers had different approaches to managing these dynamics and trying to ensure that everyone had a chance to speak, epitomised by the contrasting approaches taken by volunteers at two site 1 groups:

"I try and go around the group so that everybody, if they want to, gets the chance to talk: 'How have you been this week? Is there anything that you wanted to talk to us about?' I think there's nothing worse than you've made the effort to get there, and then nobody asks you and you don't get to talk." (Alice(V))

"It's very informal. We wouldn't be going round in a circle and saying, 'Okay, now it's your time to talk.' It's just really being in the room with the babies, having tea and coffee, the babies having a play, and just chatting about how their week has been." (Bridget(V))

Faye(V) described how volunteers learned from each other and began to tailor their approach to mothers' needs:

"I said to [the mother], 'Would you mind telling me what brought you to the group?' And she completely opened up and talked for almost the entire session, and the other peer supporter said, 'Wow, you found out more about her in one hour than I've found out about her in the last five weeks that she's been

coming'. Because they just would let people talk or not talk ... She said that it's changed how she would actually work with new people herself. It depends on the person, of course. If somebody was really timid, then I would just rather create a safe space and be 'in the now'. If people are sitting there and pretending that they're invisible, then diving in and asking them a direct question could be potentially harrowing."

The volunteers also used the group space flexibly to separate mothers who were too dominant or too distressed to participate in general conversation: *"[The mother] was quite manic and quite high, so one of us ended up talking to her separately within the group."* (Bridget(V))

# 9.3.1.3 *Negative: Pressure to talk about themselves*

Volunteers noticed that some mothers did not come to peer support wanting to talk about themselves (C), but instead wanted to listen to other women's experiences and potentially benefit from social comparison (M) (section 9.3.3 below). The volunteers were concerned that where a mother turned out to be the only person attending a peer support 'group', this inadvertent 'one-to-one' situation could create undue pressure to talk (O).

"[The mother] didn't really want to talk herself. I think she expected to have more people there. But it happened that she was alone with me and I think she didn't feel confident about it, maybe also a bit disappointed." (Wanda(V))

Emilia(V) described the different dynamics of disclosure she had observed in different groups in site 1. She interpreted these as reflecting the different social backgrounds of those attending (C), although it could also have been connected to the different facilitative styles of the volunteers, described in section 9.3.1.2 above:

"In Warwick and Leamington, they seem to have mums who are middle-class or high-middle-class, educated ... they were very restrained and very protective over their secrets... So it feels like we are taking care of their needs by being there, but not necessarily by convincing them to open up. Whereas in Coventry there is a huge array of problems that they just pour on the table and there's not enough time to deal with everything."

# 9.3.1.4 Negative: Self-censorship until trust is built

A few volunteers thought that openness was intrinsically created by knowing the other person was a mental health peer (M): "You don't go into detail of your own battles ... just knowing that you've been

through some difficult times as well is enough to bond over" (Mel(V)). Some mothers did indeed respond to peer support immediately: *"I was gobsmacked at how much information people told me within the first five minutes of meeting them"* (Nina(V)). On the other hand, several mothers and volunteers said that authentic self-disclosure took time - the knowledge that everyone present was a mental health peer was <u>not</u> necessarily sufficient to feel that they were in a 'safe space' to talk honestly. Instead, they felt able to open up as their trust in the peer supporter or the peer support group grew. Where the peer support was asymmetrical, trust was built by the volunteer demonstrating her understanding, experiences and attitude, particularly where this contrasted with the mother's experiences of talking to her friends or professionals.

"[The peer supporter]'s given me examples of experiences she's been through, and she's able to relate... Some things I say to social services and they take it in a different context to what I'm meaning. And when I talk to [the peer supporter] about it, she will take it how I mean it. I opened up a bit in my first session and in the next couple of sessions after that my trust had grown and I was able to talk to her more openly. It wasn't long before I was able to spill my guts about everything." (Julie)

The dynamics of trust in peer support groups were more complicated. Sometimes trust was built by hearing other mothers talk about their own mental health first (M), which encouraged reciprocal disclosure: *"I could say exactly what I was feeling … the fact that people were open and honest and sharing helped"* (Di). This might be used strategically by volunteers: *"It's hard for someone to articulate what they want to say straight off the bat. So there might be times that I end up sharing an experience, and seeing if that will help them start talking about how they're feeling"* (Zia(V)). As Paige observed, when everyone knew the 'shameful' secret about everyone else at a group, there was nothing to hide: *"I suppose because we all know that big thing about each other, the postnatal depression, it takes away everything else"*. However, when a mother was new to the group or attendance was erratic, there were periods of more superficial conversation, and self-disclosure was inhibited (O) until a relationship had been established (M): *"Some people only come occasionally … it can be hard if there's people who you've only seen once or twice. It makes you more anxious while you're in there, social anxiety. I hold back a bit"* (Keira).

Several mothers had tried both group and one-to-one peer support, and found that one-to-one was more conducive to authenticity:

"[At the group] I've not felt always able to completely disclose everything that is going on in my life. When I have had one-to-ones, sometimes I have come away feeling like I've got more out of that scenario, because I have been able to open up more." (Natalie)

Several volunteers reported situations where a mother had been completely inhibited from talking openly in a peer support group (M), reflecting individual social anxiety (C), and leading to disengagement or potentially to further frustration at being unable to gain emotional release (O):

"One lady came who had really quite severe issues ... When she came in I was on my own in the room, and she immediately started talking about how she's struggling with parenting, how she was struggling with her family, with her baby, with her partner, she really opened up. She spoke so much, and she just needed to talk. Then other people came into the room and she clammed up, and we started talking about rubbish like the weather. And she never came back... The women that haven't come back are usually the ones who have the greatest need." (Vani(V))

# 9.3.1.5 Negative: Self-censoring to protect others' feelings

There were also instances of mothers who self-censored (M) in a group in response to what they perceived as other mothers' views or needs, and a desire to avoid upsetting them (C), thus limiting their opportunity for authentic self-disclosure (O). For example, they wanted to avoid frightening a pregnant woman with frank descriptions of postnatal metal health difficulties, or were sensitive to different experiences of professional help:

"The first session I went to, there was only me and this pregnant girl there. I felt that I couldn't really give her the gory details. I didn't want to scare her ... [At later sessions] I'd think, 'Should I really be saying how great things are with psychology and medication, if people aren't feeling the same?'...One of the girls had been on medication for weeks and felt no different...I didn't really want to say then how good I felt." (Cora)

# 9.3.1.6 Negative: Feeling judged

There were brief allusions to self-censorship (O) and a loss of authentic self-disclosure (O) in the scenario where a mother attending a peer support group believed that - notwithstanding peer experience - the other mothers were judging her (M). This was closely related to the inhibition of honesty before the mothers attending a group had a chance to get to know and trust each other (section 9.3.1.4), and fear of being the object of negative upward social comparison (section 9.3.3.4) or negative downward social comparison (section 9.3.3.6):

"With [another mother] discussing what her circumstances were, I felt that mine was minuscule, and seemed a bit of a joke compared to her life. Me being me, typically thought, maybe she looked down on me because I'd only had very small amount of depression, where she'd battled with it for most of her life. Maybe she thought, 'Now why is this girl moaning?' That's what I felt." (Cora)

There was only one example of this theory in the context of one-to-one support. Quirat(V), who wore the hijab, described a one-to-one peer support session where the mother (who was also Muslim, but did not wear the hijab) appeared to assume that Quirat was judging her for her appearance and her husband's alcohol problem:

"As a peer supporter, you don't judge your person that you're supporting but you have to be prepared for them judging you [as judgemental] ... She was Muslim, but she doesn't wear a scarf like I do ... I came in and she went, 'Oh, you're Muslim.' And then she held back a bit in talking about her feelings ... She wanted to talk about the problems that her husband was going through and how he was coping through drinking, but she was holding back. And then she said, 'Oh, I'm Muslim as well and I don't agree with it,' like she had to justify that... It was just her viewpoint of me, it wasn't my viewpoint of her."

# 9.3.2 **Receiving affirmation**

For mothers with low self-confidence (C) or who were perfectionist and highly self-critical (C), receiving positive feedback from volunteers in response to their self-disclosure encouraged and affirmed them as parents (M) and increased their confidence (O). Sometimes this would be through identifying small successes, for example:

"[The peer supporter] was very good at celebrating the things that you'd managed to achieve, even if it was quite a small thing. Even coming to the group was, 'You got out of the door, you've got both of you dressed and you're here!' All the way through she's really helped me to feel like, 'Yes, I <u>am</u> doing better and I <u>can</u> do these things.'" (Di)

Volunteers also bore witness to a mother's progress that she did not notice in herself. Annie recollected how her peer supporter helped her to counteract negative self-talk (O) by reminding her, "'The first time I met you, you'd never have done that. You've come such a long way!'"

Volunteers tried to build mothers' self-confidence where this was low (O) by praising success at the ordinary challenges of parenthood: "We're saying to people, don't pile too much expectation on yourself ... just getting through day-to-day is absolutely fine" (Suzie(V)). They encouraged mothers to practise self-compassion (M): "They tell me I am just human, and it's all right to just have my off days and cry"
(Tilly). For mothers like Brooke who saw motherhood in binary terms as perfection or failure (C), receiving affirmation of their less-than-perfect selves (M) was a powerful antidote to self-criticism (O):

"When I say 'normal', I mean the stereotypical perfect mother, she's always got beautiful makeup, hair is looking lovely, her house looks fantastic, the children are always looking immaculate ... We joke about it in the group, 'The baby is still alive, woohoo! We've got through another week! They are still in their sleep suits, so what? If you haven't done your hair, so what?' And that's what I like as well." (Brooke)

For mothers with fragile parenting confidence (C), feeling affirmed (M) could transform their beliefs about themselves (O), especially if they did not receive positive feedback from other sources (C):

"I was so down, I was like, 'Oh, I can't do this', and [the peer supporter] was like, 'Stop, you <u>can</u> so bloody do this!' ... [The local project manager] came and seen me, and she was like, 'Wow, you are doing amazing!' ... I felt so empowered by what she'd been saying. I felt like I <u>am</u> doing a good job ... The praise has given me [crying a little] ... I feel empowered by them, like they've got my back." (Sal)

This explicit affirmation was reinforced by normalisation of a mother's feelings and experiences when peers said that they had felt the same. This is explored in the next section.

# 9.3.3 Peers talk about themselves: social comparison

When peers talked about their own experiences of mental health and parenting, there were opportunities for social comparison. This formed the basis for two major positive outcomes (overcoming shame, and hope for recovery) and one less prominent positive outcome (perspective), as well as the negative outcomes of feeling abnormal, discouragement, self-criticism and disappointment.

#### 9.3.3.1 Positive lateral comparison: normalisation

Normalisation helped mothers to overcome internalised stigma (O), and develop confidence and selfacceptance (O): "[In peer support] the abnormal become normal and it gives you the power and energy ... you don't need to feel like you're worthless" (Yasmin(V)). Normalisation occurred through lateral social comparison when a mother realised she was not alone (M) in her 'failure' to conform to the cultural norm of contented motherhood (C). This enabled mothers to contextualise their own experiences and emotions within a broader definition of normality, summarised by Wanda(V): "Parents in Mind helps to demolish this stereotypical vision of motherhood, how cheerful it could be and glorious and colourful, and actually it's not. It can be just a normal life, when you have your ups and downs, and sometimes downs affect you more than ups." For some mothers this primarily meant reassurance that they were not alone in struggling to cope with the challenges of early parenthood, and consequently that finding things difficult did not mean *"you're an alien, or a bad mother"* (Vani(V)).

"[The volunteer] is dead honest. She's like, 'Yes, it's shit.' ... All the other mums just seemed like me, knackered. So I wasn't walking into mums that had it all together and were, 'We love this.'" (Paige)

For other mothers, normalisation was closely focused on experiences of more serious mental health difficulties and treatments. For example, Hema had intrusive fears about her baby's safety, and Rosie had felt ashamed of taking anti-depressants:

"One mum mentioned that [she had similar fears], and my mind and my heart - I felt weak! I thought, 'Oh my God, this is normal! This is not just me that's scared of everything!'... And as soon as you start to think it's normal because you've got other mums that are going through it, I accepted that it's OK to feel like that." (Hema)

"[Peer support] has made me feel less anxious, because that was a lot of my problem, what people would think of me... There's people there that take medication and think it's okay ... That makes me feel like I made the right choice." (Rosie)

Some interviewees, like Wanda(V) quoted above, saw a wider definition of 'normal' motherhood as including both good and bad times, which normalised a range of emotional reactions. Others, however, represented 'normal' life with a young baby as fundamentally hard and unhappy: *"It should be the time of your life, but it's not, it's a bit shit"* (Cathy(V)). They saw peer support as the only place where women were honest about this negative reality, and where unhappiness could be affirmed as a normal reaction to this normal experience: *"If you feel shit in this shit time, that's okay"* Mel(V). From this perspective, part of the work of peer support was therefore challenging mothers' assumption that most other women coped well with motherhood, and potentially substituting a belief that most did not, but were hiding this: *"We've spoken a lot about mums that we see, and we call it the 'café culture' and the 'yummy mummies', and how they all look to be coping really well ...[but] you don't know what's happening behind closed doors"* (Vani(V)). While Cathy(V) celebrated the uniquely honest environment of peer support, she also suggested that the requirements of the normalisation of unhappiness might override the requirements of honesty from volunteers:

"We've had one lady who said, 'If I'd realised it was this hard I wouldn't have done it.' We applauded her honesty, said that we'd all felt like that at some point ... They always ask [the volunteers], 'How's <u>your</u> week?' It is important to say, 'I've had a terrible week' ... it normalises the feelings they have." (Cathy(V))

For some mothers, the self-acceptance that flowed from normalisation enabled them to feel ready to talk about their mental health with family and friends (O): *"I feel like I can tell others without being ashamed of how I felt. Which I would never do before"* (Annie). This restored their ability to have genuine confiding relationships outside peer support (O): *"It was really good to hear that we managed to help people communicate better with the ones that are important to them, because we will be in their life one day and the next day we won't be there"* (Emilia(V)).

For other mothers, normalisation within a reference group of peers made them feel better, but did not give them the confidence to admit their feelings in non-peer settings: *"[The local project manager] talked about how it would be good to transition from the Parents in Mind group to the playgroup...but I never felt like I wanted to do that. I'd rather stay in the smaller group where I can be more myself"* (Di). Some volunteers questioned whether the creation of a parallel 'normality' removed from the mainstream was genuinely helpful if mothers could not then move on from peer support and function in 'normal' social settings. This reflected the debate on the purpose of peer support among staff described in section 7.5.5.

"They're making very tiny steps of facing the real world and if we just create this amazingly safe environment without anything changing, I'm not sure that we are doing what we are supposed to do, which is to give them the strength to move on." (Emilia(V))

# 9.3.3.2 Negative lateral comparison: discouragement, lack of peer feeling

There were two negative mechanisms identified where lateral social comparison in groups might make a mother feel worse. A mother who hoped to 'recover' (C) might feel discouraged (O) when meeting other mothers experiencing the same mental health condition, if that normalised the status quo of being unwell (M): *"I don't feel comfortable around [another mother with the same diagnosis], because she keeps reminding me of my issues and it makes me feel discouraged about getting better"* (Flo).

By contrast, some mothers felt bored and did not experience normalisation (O) if they could not identify with others' mental health experiences (M): *"Listening to what other people are struggling with isn't always relevant to your own experiences"* (Natalie). Peers were not necessarily a useful reference group for social comparison unless they had more in common than lived experience of perinatal mental health difficulties: "I would <u>like</u> to say it would be good to have as much as diversity in those groups as you can. But I think the <u>reality</u> of it is, in those times of vulnerability and stress you need to connect with people who are similar to you and we just really weren't that similar" (Wendy).

There was, however, no evidence for the hypothesised mechanism that mothers would feel a lack of validation (O) if peers' attempts to normalise feelings were experienced as minimisation (M). No one said they had experienced peers minimising their feelings, although some mothers appeared to minimise the legitimacy *of their own* feelings if they believed that other mothers had more difficult lives or were suffering more than they were (section 9.3.3.6).

#### 9.3.3.3 Positive upward comparison: hope

Many volunteers identified upward social comparison as an important mechanism, leading to hope for recovery (O). They believed that they could be role models providing *"living proof"* that perinatal mental health difficulties could end (M), and that this mechanism was specifically activated in the context of fear that poor mental health was a permanent situation (C):

"Mums do tend to like the fact that we've been where they are, but look at us now. We're dealing with it. There is a future .... It helps them to see that there's light at the end of the tunnel" (Laura(V)).

Bridget(V) highlighted the unique power of this peer testimony compared with a comparable reassurance from a professional:

"It's very easy for a health professional to say, 'You'll be fine. This will pass, blah-blah-blah.' But for someone to say, 'We've all been there, we've all struggled, we've gotten through it. It's not going to be like this forever.' That's so much more beneficial than some person who's just read a textbook telling you."

Some mothers also referred to this mechanism giving them hope for the future, when they would be restored to 'normality': "Just to say, 'This isn't a permanent change' - the reassurance that it will go back to normal" (Wendy). Rosie observed that the dynamic of hope was primarily between volunteers and mothers, but Grace had also experienced it in seeing other members of her peer support group gradually feel better. Keira found that comparing herself upwardly to other mothers in the group, in the specific sense of their greater socio-economic advantage, had helped her to overcome self-blame:

"[In a one-to-one] you can see that people have got past it and come out of the other side and I find that quite positive for me... [But in a group] you are with all the other women and they're obviously still going through problems and I'm still going through problems and that's why we're at the group." (Rosie)

"In the beginning, I really didn't have any hope that things would ever be better ... I did find it helpful ... to see how people [in the group] keep getting better." (Grace)

"[The other mothers] have similar experiences but different backgrounds. It's nice to know [perinatal mental health difficulties are] nothing to do with anything I've done, or me not going to university, not working, or being single ... It's nice to know that people who you would think would have it all together, people with a good job, and married, and loads of support, can struggle too - so you stop thinking it's your fault." (Keira)

Volunteers were aware that 'recovery' was not inevitable, so it was more appropriate to be a hopeful role model than to give reassurance: *"We're not supposed to say to someone, 'It gets better', just in case it doesn't... we are a living example that things <u>can</u> get better" (Rachel(V)). This also sidestepped the precise details of what was meant by 'recovery', which did not necessarily imply being completely free of mental health difficulties: <i>"There is light at the end of the tunnel insofar as we are fully functioning ... we've gone back into work"* (Penny(V)).

#### 9.3.3.4 *Negative upward comparison: disappointment, self-criticism, loss of peer feeling*

Some volunteers recalled situations where upward social comparison (M) in horizontal peer support had not given mothers hope, but instead caused disappointment (O) and self-criticism for failure (O) where another mother was recovering more quickly or overcoming her problems. The personal contextual factors were unclear, but might be inferred to be low self-esteem or a negative attribution style:

"There are cases where they leave more disappointed than they come ... Even if it's someone you like and feel connected to, it's still that comparison and competition in your head: 'Why am I not getting better? ...We started at the same point, and she's ahead of me." (Emilia(V))

Cora described negative upward social comparison from the perspective of being the mother who had 'recovered' more, resulting in the loss of peer solidarity: *"This other mother's not found that same route* [to recovery] as me ... I can compare it to a dieting group I used to go to. When you start off and you're all in the same boat, people really understand. But when you get to your goal, people aren't the same with you anymore. They'll then say, 'You're too thin' or they're negative in a way that makes you feel uncomfortable. I think sometimes your success can sometimes put people off."

#### 9.3.3.5 *Positive downward comparison: perspective*

Several mothers described how meeting others whose mental health was poorer than their own, or whose lives appeared to be more difficult (M), had given them a helpful new perspective on their own

problems (O): "Listening to other people's stories ... helped me appreciate the things I did have as well, because other people weren't as lucky ... It helped me to get that perspective and gauge that some things in my life are wonderful" (Di).

Some mothers also gained this perspective over time, as new mothers joining a group provided a yardstick against which to measure their own progress: *"Hearing people who were starting out on their journey, I was able to support and sympathise and empathise with them and, in doing that, realise how far I've come."* (Wendy)

# 9.3.3.6 Negative downward comparison: self-criticism, fear

Some mothers said that downward social comparison had been demoralising, as this had made them self-critical about failing to cope (O) when they realised that other mothers' problems were greater (M); including both mental health and social circumstances. Wendy described this as *"the privilege that I have, both financially and mentally."* Section 9.3.1.6 has illustrated how some mothers externalised this feeling, and assumed that the other mothers judged them as weak, but several experienced this as inward guilt (O): *"[Another mother] had these great horrible things to deal with, and I felt guilty for having my issues when I'm not going through a similar thing"* (Lena).

In addition, hearing about someone else's worse experience could be frightening (O) for a mother who worried that this was what lay ahead (M), as was understood by the mothers who self-censored to protect others (section 9.3.1.5). Rosie had experienced this at a large peer support group run by a different organisation:

"One woman said to me, 'It gets really bad. You've got to get yourself to rock bottom,' and I was thinking, 'Oh my gosh. So it gets even worse than this?' And that really knocked my confidence. You hear other people's experiences and some of it is not what you want to hear." (Rosie)

# 9.3.4 **Peers share ideas for self-care, parenting and mental health treatment**

# 9.3.4.1 **Positive impact: new information and motivation**

Many mothers wanted new ideas about self-care, parenting and mental health treatments (C), and trusted experiential knowledge as a reliable source of information (C). When peers shared their tips for coping with motherhood and mental health, mothers gained access to credible information (M) and the motivation to act on it (M). This led to increased parenting confidence (O) and coping strategies that they put into practice (O).

"[The volunteer] has so much experience, it's as if she has experienced everything that all of the ladies in the group have experienced ... she will say, 'Have you tried this?'... So it's just little tips and tricks, it's very much example-based so you believe it, it's not from a textbook... And from some of those sharing experiences, I have got some really good advice." (Brooke)

Although mothers often referred to receiving 'advice', volunteers were specifically trained to talk about options rather than to give recommendations: *"We're not everybody's problem solver*" (Tanya(V)). Several volunteers articulated the psychological rationale: where information was given in an explicitly non-directive manner, this could empower the mothers (M) in making their own decisions, increasing their sense of agency and confidence (O). Some appeared to be very skilful at navigating this boundary.

"The big thing is we don't give advice ... Not saying, 'You should do this or you need to do this.' Only using phrases like, 'Have you thought about doing this?', or 'Have you heard of anyone doing this?', or 'Have you thought of any other ways you can do this?' A lot of the time the personal strategies would have been disguised by saying, 'Some women do this.'" (Bridget(V))

Some mothers and volunteers felt that information and advice primarily came through the asymmetric relationships of volunteers and mothers, whereas others reported it also occurring horizontally between mothers attending a peer support group.

"When there was a group situation and there was peers who also had babies, you can sympathise, but it really didn't feel like you were getting any advice from each other." (Wendy)

"What I liked most about the groups was seeing the other mums interact with each other... they're asking each other for advice." (Laura(V))

As mothers came to peer support with widely differing needs, resources, and mental health and parenting experiences (C), their perception of the importance of this mechanism varied from incidental (for example, Grace) to fundamental (for example, Annie). The perceived cultural differences in the acceptability of self-help strategies have been described in section 7.5.6.

"With the perinatal team, it's all that problem solving: 'Here is a strategy, here is how you can challenge thoughts for next week'... [At Parents in Mind] we might discuss mindfulness or meditation or strategies for changing thoughts but they wouldn't be the aim of the session. The aim of the session would be more to just talk to each other and relate." (Grace) "The best thing [the volunteer] did was she told me to write a journal and only keep positive things in there to read back. To remind yourself you do have good days, and I still use that journal." (Annie)

#### 9.3.4.2 Negative impact: non-evidence based advice, disappointment

There was a constant tension between mothers' desire to gain access to volunteers' experiential knowledge about how they might manage their mental health or recover, and volunteers' commitment to give non-directive information that was not primarily based on their personal experience. The trainers were alert to the difference between what might be intended by a volunteer and how it might be heard by a mother, and one believed that it was inappropriate for volunteers to talk about coping strategies at all because this might be misconstrued as advice:

"Even though the peer supporter knows it is equal, the mother will not. So when the peer supporter says 'Let's share our self-help strategies', the mother will feel she's been given some advice even though she hasn't ... It's helping volunteers to realise the difference between normalising someone's experiences and that commonality, versus accidentally telling someone what to do. And that can be quite a fine line, particularly if the person <u>wants</u> you to tell them what to do" (trainer, site 2).

Some volunteers were aware that by respecting the boundaries of peer support, they were disappointing (M) mothers who specifically wanted clear advice on overcoming mental health difficulties (C): *"One of the ladies kept saying to me, 'I want to be fixed!" and I didn't know what to say to her"* (Quirat(V)).

Although the volunteers were trained not to give their opinions about medication or psychological therapies, other mothers at the group freely exchanged their opinions in ways that were not always supportive of impartial decision-making: *"They just say it all!"* (Josie(V)). If a mother was influenced by inaccurate information or misleading advice from peers (M), she might lose confidence in mental health treatments or risk disappointment if a treatment did not work for her (O): *"People will say, 'I tried this medication and it was amazing.' ... You could get your hopes up and think that it could be amazing for you and actually it won't be"* (Rosie). Part of the volunteers' role was to remind mothers that experiential knowledge was not necessarily transferable:

"We have had one or two that say, 'CBT didn't work for me' or 'I was on those tablets and they didn't work.' We had one mum who listened to what everyone said, and because she took on board what the other mums had said, she felt like she needed to change everything she was doing... A volunteer took her

to one side and explained to her that just because it had not gone right with one person doesn't mean she needs to go back and change everything she did." (Laura(V))

# 9.3.4.3 *Limitations on support for practical issues*

Some mothers had mental health difficulties that were entwined with their social circumstances, such as poverty, homelessness or insecure immigration status. It had been hypothesised that peer supporters would be able to reduce stress by helping mothers to resolve their practical problems, and they did insofar as these issues related to motherhood. However, the boundaries maintained by Parents in Mind meant that mothers in difficult circumstances did not receive direct support to address their underlying problems:

"[A mother] wanted housing advice... I could have given her common sense advice and I have a background where I used to work in housing, so I could have given her quite a bit of advice about what to do. But I didn't because obviously the boundaries are set." (Uma(V))

# 9.3.5 **Signposting to mental health and community services**

Volunteers also used a non-directive approach when signposting mothers to other community groups or services, or orientating them to what was available if they were unfamiliar with the local area or with maternity and child health services (C). As with the sharing of self-help and parenting ideas, mothers thus gained access to information they trusted (M) and in some cases the motivation to act on it (M), which could potentially lead to increased uptake of services and support (O): *"We talked about different groups going on, we looked at things that might be good or interesting to do. I started going to a few more groups and finding out what was going on in the area"* (Natalie). This theory was only a minor feature of mothers' accounts.

There was no evidence for the hypothesised theory that signposting plus normalisation would also lead to increased uptake of mental health services among women who were previously unwilling to try them. This may reflect the high proportion of mothers who were already clients of mental health services, or were referred through professionals who were also referrers to those services. Some volunteers said that they encouraged mothers to talk to their GP about accessing medication or therapy, a message that was not necessarily non-directive: *"You say, 'Talk to your doctor, tell your doctor, they're there to listen, aren't they? Speak to your doctor; ask your doctor'* (Josie(V)). There was no evidence about whether this encouragement had affected mothers' behaviour.

There were several examples (described in section 7.5.9) where the local project managers had interceded with perinatal mental health services to persuade them to support a mother whose needs were greater than the volunteers could manage safely. These situations did not give rise to peer support mechanisms, but showed how a third sector programme with committed and caring staff could support a mother to access mental health services where the door had previously been closed.

# 9.3.6 **Peers use therapeutic techniques**

# 9.3.6.1 *Reframing and small mastery experiences*

In addition to active listening and affirmation, some volunteers (and local project managers) used other therapeutic techniques in their interactions with mothers, usually gained as a result of their previous professional experience. One technique was reframing: where mothers had entrenched negative perceptions (C), the volunteers offered alternative interpretations and perspectives to enable mothers to see situations in a different light (M) and thereby feel more positive (O):

"I was absolutely terrified that I wasn't going to love my youngest child, because I didn't want him in the first place ... [The local project manager] said to me, 'From talking to you, there is not one doubt in my mind that you are going to love this child. I can hear in your voice that, <u>because</u> you want to love this child, that's why you're so anxious. And it's not because you're not going to love it; it's because you're frightened that you can't give it enough love'. And it was! That's what it was!" (Sal)

Where mothers felt overwhelmed with what felt like big challenges (C), a second technique was for volunteers to break these down into small, achievable steps so that mothers could build their confidence (O) by a series of incremental mastery experiences (M):

"A lot of it would be suggesting, or trying to come up between us, little things that she could do during the week to make those tasks that seemed huge, smaller ... She was so panicked that she sometimes just couldn't see the simple solutions." (Bridget(V))

Empathy could guide volunteers in knowing when it was appropriate to challenge a mother's negative cognitions and when to accept them: "[The mother] felt like this is the time for her to moan, to cry, to let go all her negative feelings ... If they are in the mode of complaining, they don't want to hear, 'Oh, there is something positive about it'" (Wanda(V)).

# 9.3.6.2 Lack of therapeutic techniques

Where mothers had negative perceptions (C) but volunteers did not have the skills to reframe these, the freedom mothers felt to express negative thoughts could potentially lead to a culture of negativity at a group (M), reinforcing negative feelings about motherhood (O).

"I think it could be a place where you're just encouraged to whinge. What would have been good is to have a slightly more structured discussion of everything that's really annoyed you or got you down, and then finish by saying 'Can anyone say what's made them feel really happy?' so you can finish on a positive." (Wendy)

In addition, some mothers really wanted professional support (C) (see section 8.3.2). These mothers were disappointed (M) that peer supporters did not have more specific therapeutic techniques to offer, and may have had difficult feelings stirred up without sufficient support to deal with or resolve these feelings (M), leading to reduced emotional wellbeing (O): *"When people have complex mental health issues, there's always a part of you that thinks, 'Did I unravel something which they maybe didn't speak to me about?"* Uma (V). This put volunteers in a stressful position when they were aware that peer support was not helping a mother in the way that she needed (see section10.2.5.2).

# 9.3.7 **Opportunity to support others: helper-therapy**

A few mothers mentioned the psychological benefits of being able to help other mothers (M), usually at a point where they felt more 'recovered' (C): *"I am back to being me and if I can encourage somebody else ... it's good to be able to offer that to other people"* (Grace). Morgan felt that this gave meaning (O) to her mental health difficulties: *"It's nice, because then you feel like you've not gone through it for nothing."* Hema connected this mechanism to her personality (C): *"In my nature generally I am a quite helpful person ... That part was really rewarding."* 

# 9.3.8 **Opportunity to make social relationships**

# 9.3.8.1 *Positive: new friendships*

Some mothers who had previously felt lonely (C) had been able to make friends (M) and overcome their sense of social isolation (O), where the same women attended a peer support group regularly: *"The service has saved me from isolation and made me feel more positive - finding friendships has been a real achievement. I was totally new to the area and Parents in Mind has helped me to feel more settled"* (WR12). Some found the group itself provided the social support they wanted, while others used social media to chat in between sessions, or had begun to meet socially beyond the group.

A few mothers said they were happy with the friendliness at the group, but did <u>not</u> want this to lead to ongoing relationships which might incur burdensome social obligations:

*"It's very much turn up, have the relationship there and then that's it, which I think is helpful, it's less pressure ... If you have to build a friendship then you've got to maintain it and I think as a new parent, you can have difficulties in terms of what time you've got available."* (Oona)

It had been hypothesised that some mothers who joined an established peer support group might feel excluded (M) if they perceived an existing friendship clique had formed. None of the mothers interviewed mentioned friendship cliques, although as described in section 9.3.1.4, mothers' sense of security in a group was closely linked to getting to know others who attended regularly. Volunteers worked hard to ensure that newcomers felt included: *"Every time someone new came, one of the volunteers would pretty much be with that person the whole time, making them feel comfortable"* (Wendy). There was, however, a hint from Cathy(V) that it was more comfortable to volunteer in a group with only 'regulars': *"The ladies that come along ... they've got a little friendship group going. We've been quite lucky because the two new mums that we had since December have not come much"*.

# 9.3.8.2 Negative: relationship failure

There were some lonely mothers who were disappointed or experienced social failure (O) because they had not managed to form friendships (M) through peer support. Particularly at sites 2 and 3, attendance at some of the peer support groups was so erratic that there was little opportunity for mothers to get to know each other: *"I didn't build up a friendship with anyone else in the group because they would sometimes drop in and sometimes not"* (Wendy). Other mothers in the group might not want to become friends (like Oona quoted in section 9.3.8.1), and mothers with social anxiety might find friendship hard in any situation (C): *"I have a lot of social anxiety, so maybe [not making friends] could be to do with my own confidence"* (Tilly).

In addition, mental health peer experiences were not necessarily a strong basis for ongoing social relationships for mothers with divergent interests and personalities (C): *"There isn't a genuine friendship there. You're there because you've got something in common but it doesn't necessarily make you friends"* (Natalie). Some mothers had experienced social failure (O) when relationships that had begun to feel to them like friendship ended in rejection (M):

"One lady was quite attached to the first one who left. She was there in the group when her new friend said, 'I'm moving on.' Her face dropped, and we realised she was very uneasy about it. She stopped coming the next week ... She just cut contact with everyone, with us and with her new friend." (Emilia(V))

# 9.3.8.3 *Endings*

It had been hypothesised that the ending of peer support might leave a mother feeling bereft of social support if she was reliant on it. There was a some evidence that this had happened when the local project manager at site 1 tried to 'move on' a few mothers who had attended a group together for many months, before the support model was changed to offer each mother a limited number of sessions. She reported that they initially reacted with feelings of upset and rejection. This appeared to be an isolated incident, with the revised model managing mothers' expectations more effectively. Most mothers said they stopped peer support when they felt ready, when their baby became mobile so they could no longer sit still and chat, or as part of a natural break at the end of maternity leave. Annie reflected that the ending of her one-to-one support was sad, because she had a real relationship with her volunteer, but she understood the reason and did not feel bereft: *"There's another pregnant women waiting for [the volunteer] to help her....It's sad for me but someone else is going to gain from it."* 

9.3.9 Peer support provides routine

#### 9.3.9.1 *Positive: appreciating structure and a place to go*

For mothers living with the chaos of early motherhood (C), the inertia of depression (C), or the fearfulness of social anxiety (C), a regular peer support group helped to structure their time and provided a reason for leaving the house (M), enabling them to feel more purposeful and in control of their time (O), and with a reason to self-care (O): *"It's nice to have some routine as well … It breaks the month up so you can go from Tuesday to Tuesday and then you can talk about it, and then you have to go to another Tuesday."* (Keira)

#### 9.3.9.2 *Negative: letting people down*

Having a routine meant that missing a one-to-one session, or arriving late to a poorly attended group, was another source of guilt (O) for a couple of mothers: *"It's hard to get out of the house and there were days when if I was five or ten minutes late, I would feel awful and I would really pile a lot of pressure on myself"* (Vicki).

#### 9.3.10 Peer support from volunteers

#### 9.3.10.1 *Positive: volunteering means they care*

Volunteers tried to create a warm atmosphere at the groups, and to show their care through attentive kindness and hospitality: *"At times just a hug because sometimes they've not had any human contact apart from that baby"* (Cathy(V)). A few mothers said that the volunteer nature of the support increased their sense the peer supporters really cared about the mothers (M), so they felt nurtured (O):

"To feel like people have given up their time to help ... It feels like a family. It might be a weird way to put it but as you walk into the group, the first thing that one of the ladies says is, 'Oh, do you want a brew?' I know it sounds like a stupid thing, but it's the only brew that anybody makes me in the week." (Oona)

There was not, however, any evidence for the hypothesised mechanism that being offered one-to-one support by a volunteer would increase the mother's self-esteem by making her feel that she was <u>worth</u> a volunteer's time.

#### 9.3.10.2 Negative: volunteering means limitations on the support

Other mothers, while appreciating that volunteers were giving their own time to the peer support, highlighted the limitations this sometimes imposed, for example the closure of groups during the school holidays, and feeling let down if a volunteer was not available (M). This was particularly challenging for mothers who appreciated the structure that peer support gave their week, and for those who felt reliant on it to manage their emotional wellbeing (C):

"It's been a bit hit and miss with me and [the volunteer]. I understand completely that she is a volunteer, and obviously, she's got a life, and she works as well, but on my bad days, I don't care about that. It's like, 'Oh, I need you now!'" (Sal)

Another limitation of a volunteer programme was that, in order to keep everyone emotionally safe, peer support was occasionally withdrawn if a mother became too unwell. This could mean that a mother in a mental health crisis was supported to access more appropriate services (see section 7.5.9), but it could also mean that a mother lost her only support at her time of greatest need:

"I had some really bad episodes over the weekend and it was decided that I need to go and find other support until it goes back into the mild-to-moderate. And it's fair enough because it's volunteers and they're not trained to deal with particularly bad things. ... [But] it would have been good to carry on because although I have been in touch with the mental health service, nothing has happened yet. Everything is so slow, so it suddenly feels like no support from anywhere." (Lena)

#### 9.4 Summary of the differences between group and one-to-one support

The ways in which peer support could work differently in group and one-to-one settings have been noted in the sections above. Most of the positive C-M-Os were found in either setting, but only a peer support group offered mothers the opportunity for downward social comparison (realising others have greater problems), helper-therapy (the opportunity to help others at the group), and increased social support through making new friends. By contrast, almost all of the negative C-M-Os were identified only in group settings: not feeling heard; feeling unable to talk honestly; feeling unexpectedly pressured to talk because the group was poorly attended; self-censoring to protect other women's feelings; feeling different from the others at the group; horizontal social comparison (feeling discouraged about recovery); upward social comparison (feeling discouraged that others have made faster progress); downward social comparison (feeling weak and judged when seeing that others have greater problems); receiving inaccurate or directive advice about mental health treatment and parenting; feeling depressed by a focus on negative feelings; and the failure of attempts at friendship.

# 9.5 Differences between peer support and professional support

The programme theories analysed above indicate some mechanisms that are unique to peer support (e.g. those relating to social comparison and experiential knowledge), and others which may be shared with some forms of psychological therapy (e.g. feeling accepted and feeling able to speak freely). Mothers who were interviewed had a range of positive and negative experiences with a variety of types of professional support for past or current mental health difficulties. As described in section 8.2, they also had a range of expectations about how peer support might differ. When they reflected on how peer support had *in fact* differed, some emphasised that it felt like a different experience because peer supporters accepted the mother without pathologising her.

"Parents in Mind was the only one that I actually felt comfortable with ... When you're doing counselling, they're just sat there writing things down, it's as if they're feeling sorry for you, the way that they talk to you. But it's not like that in the [peer support] group - they don't look down on you, or as if they're giving you sympathy, because I hated that... It's lovely to be around people where they look at you as a person, and not what you've been through." (Morgan)

Peer support was based on equality whereas professional support (no matter how good) embodied a power differential, which could be seen as implicitly judgemental, and placed the mother in a position of supplication for help: *"I don't feel like the peer supporters are actually putting themselves above us or* 

saying, 'Oh, we're much better now,' it very much feels equals" (Grace). Some mothers had experienced professional support as more goal-orientated and recovery-focused than peer support. For Wendy, it had felt like a Talking Therapies group started from the 'illness', whereas peer support started from the individual. On the other hand Di valued peer support as an opportunity to talk, but had then asked for professional support to help her move forward.

"The professional approach was much more clinical in terms of understanding the psychology behind it. We worked through models and diagrams. It wasn't personalised at all. And then the peer support group really was just, 'How was your week?'" (Wendy)

"I felt like I had the outlet to talk in the peer support group, but I wanted to understand a bit more about what was going on in my head and how I could change those thought processes to be more positive." (Di)

Almost all of the mothers had been able to decide for themselves when to move on from using peer support. Keira described how supportive she found the inclusive approach, where success was celebrated without assuming a linear path to recovery.

"It's nice to have the relaxed atmosphere [at peer support], so even if you've had a good week you can come and it's like 'Yay, you've had a good week!' not [stern voice] 'You've had a good week so you don't need to come'. I've found in the past with the mental health team, if you're doing well they step back, but then you're not always doing well."

# 9.6 Comparison between initial theory of change and final theory of change

The final theory of change for Parents in Mind included 16 positive C-M-O configurations and 12 negative C-M-O configurations relating to the impact of peer support on mothers. In Table 23, the final theory of change is compared to the hypotheses of the initial theory of change.

# Table 23 Comparison between initial and final theory of change for impact on mothers

Context – individual level	Mechanism		Outcome	Initial	Final
	Resource – What happens at peer support	Mother's reaction or reasoning		theory of change	theory of change
Shame: feels a unique failure as a mother. Hides feelings from partner, family & friends & can't meet needs for authenticity in relationships.	Peers listen non-judgementally, empathetically, confidentially	Feels understood and accepted: safe to talk honestly	Emotional release, self-acceptance, self-esteem, disclosure to family and friends	1	1
	Peers do not listen /time pressure	No opportunity to speak	Self-censorship, no emotional release	x	1
Avoids new parent groups as these make her feel worse.	Peers listen, erratic attendance at group	Feels judged, not safe to talk honestly, wants to protect others	Self-censorship, no emotional release	x	1
Low self-esteem, negative attribution style.					
Does not want to talk about herself	Group poorly attended	Feels pressured to talk	Discomfort	х	1
Low self-confidence, perfectionism	Peers give positive feedback, encourage self-compassion	Feels affirmed and encouraged, more self-compassionate	Self- confidence, self-esteem, self- compassion	1	1
Shame: feels a unique failure as a mother	Peers talk about themselves	Realises others feel the same (normalisation)	Overcomes shame, self-acceptance, disclosure to family and friends	1	1
Shame: feels a unique failure as a mother	Peers talk about themselves	Realises others feel the same	Feels discouraged about recovery	x	1
Negative attribution style		Does not identify with peers	Reinforced feeling of abnormality, no emotional release	1	1
		Normalisation feels like minimisation	Feelings are not validated	1	x
Worries she may never recover	Peers who are more recovered talk about themselves	Realises others have recovered	Hope for recovery	1	1
Worries she may never recover Negative attribution style	Peers who are less recovered talk about themselves	Sees others have made faster progress	Discouraged, self-critical	x	1
Lack of perspective	Peers talk about themselves	Realises others have greater problems	Gains perspective	1	1
Shame: feels a unique failure as a mother.	Peers talk about themselves	Realises others have greater problems	Feels weak and judged	1	1
Negative attribution style					

Context – individual level	Mechanism		Outcome	Initial	Final
	Resource – What happens at peer support	Mother's reaction or reasoning		theory of change	theory of change
Lack of parenting confidence or coping skills	Peers share non-directive ideas on self-care and parenting	Gains strategies for self-care and parenting and feels motivated to try them	Parenting confidence, coping strategies, empowerment	1	1
Lack of parenting confidence or coping skills Wants advice about treatments	Peers share directive ideas on mental health treatment and parenting	Influenced by directive advice from others in group	Disappointment if advice does not work Loss of confidence in mental health services	1	1
Wants advice about treatments	Peers do not give advice or share details of treatment	Disappointment that no advice given	Frustration	x	1
Practical problems e.g. financial, housing	Peers offer support to solve practical problems	Help to solve practical problems	Reduced stress	1	x
Lack of knowledge about local services	Peers signpost to community services	Feels informed and motivated to try community services	Uses appropriate support	1	1
Needs professional mental health support	Peers signpost to mental health services	Feels informed and motivated to try mental health services	Uses appropriate support	1	x
Low self-confidence, negative attributions	Peers use therapeutic techniques	Gains different way to see situations and small mastery experiences	Increased positive thoughts, self- confidence	1	1
Wants access to therapy, negative attribution	Focus on negative feelings, peers do not use therapeutic techniques	Dwells on negativity, disappointment that no techniques used, emotions stirred up but not resolved	Negative perceptions of motherhood reinforced, reduced emotional wellbeing	5	1
Recovering from symptoms, altruistic	Opportunity to help others at group	Supports other mothers	Satisfaction and meaning	1	1
Social isolation, seeking friendship	Regular attendance at group	Makes new friends	Reduced loneliness	1	1

Context – individual level	Mechanism		Outcome	Initial	Final
	Resource – What happens at peer support	Mother's reaction or reasoning		theory of change	theory of change
Social isolation, seeking friendship	Irregular attendance at group, peers do not want friendship (group only)	Attempts at friendship unsuccessful	Feelings of social failure	1	1
	Peers form friendship cliques (group only)	Feels excluded from clique		1	x
	Peer support is time limited	Ending leaves mother feeling bereft of social support		1	x
Life with a baby feels chaotic and lacks structure	Peer support provides routine	Gains structure	Feels more in control	x	1
	Peer support provides routine	Peer support becomes a social obligation	Self-critical for missing sessions	x	1
Low self-esteem	Peers are volunteers	Believes peers really care	Feels cherished	1	1
	1:1 support from peer who is volunteer	Feels she is individually worth a volunteer's time	Increased self esteem	1	x
Reliance on peer support	Peers are volunteers and sessions are not reliable	Feels let down	Difficulty coping when peer support not available	x	1

# Key

Italics: New contexts, mechanisms or outcomes that were in the final but not the initial theory of change

Strikethrough: Contexts, mechanisms or outcomes that were in the initial but not the final theory of change

Positive mechanism

Negative mechanism

#### 9.7 Chapter summary

This chapter has explored the complexity of the programme theories operating within the Parents in Mind change model for mothers. Non-judgemental, empathetic, confidential, active listening could make a mother feel understood and accepted; positive feedback could make her feel affirmed and encouraged; peers talking about their own experience of mental health and parenthood could normalise her experiences and enable her to realise that others have recovered or had greater problems; sharing non-directive ideas about self-care and parenting could give her new strategies and the motivation to try them; signposting to community services could give her information and motivation to try them; occasionally using therapeutic techniques could give her different ways to see situations and small mastery experiences. In addition mothers could benefit from the dynamics that could develop through regular group attendance: the opportunity to make friends, the satisfaction of being able to help other mothers, the routine of regular meetings providing structure to the week, and the fact that the peer supporters were volunteers leading her to believe that they must care.

Some of the negative mechanisms occurred when these activities were absent - for example, the mother did not feel she was listened to; she was influenced by unhelpful directive advice from others in the group; she was frustrated that peers withheld information about their own experience; peers did not have therapeutic techniques to challenge a culture of negativity and so her negative perceptions of motherhood were reinforced; and erratic attendance at groups (or other mothers not wanting friendship) meant experiences of social failure. Other negative mechanisms occurred in response to the same activities as those that triggered positive responses from mothers – for example, peers listening could feel like pressure to talk; peers talking about themselves at a group could make the mother feel that she didn't belong, that others were making faster progress or that she was weak to be distressed when others had greater problems; routine could make peer support feel like a social obligation; and the fact that peer supporters were volunteers could make sessions unreliable. All interviewees felt that the positive impacts of peer support far outweighed the negatives.

There were statistically significant improvements in median depression and anxiety scores as measured by the Hospital Anxiety and Depression Scale. Although these cannot be relied on as direct evidence of impact, in the light of mothers' own causal attributions they indicate the likelihood that the subjective outcomes described in this chapter could, for some mothers, lead on to measurable impact on symptoms of anxiety and depression. For other mothers, particularly those with more severe or more

long-term mental health difficulties, peer support could lead to a better quality of life with improved coping and subjective recovery.

The next chapter explores the positive and negative contexts, mechanisms and outcomes for the volunteers, and what is needed to support their emotional well-being, to answer research questions 4 (the change model for volunteers), and 6 (support for the emotional wellbeing of volunteer peer supporters).

# **10** Parents in Mind Study - Results, Part 4 (Impact on Volunteers)

# **Chapter overview**

This chapter presents the fourth part of the results of the primary research, answering research questions 4 (the change model for volunteers), and 6 (support for the emotional wellbeing of volunteer peer supporters). This chapter begins with an overview of the final theory of change related to impact on volunteers. It describes how the volunteers benefited from their training and their volunteering, experiencing some of the same positive peer support mechanisms as the supported mothers, as well as others specific to their role. It also describes how offering peer support had the potential to undermine volunteers' emotional wellbeing. Finally it considers how volunteers were affected by the confusion about sharing their lived experience, and presents volunteers' views on the support available through Parents in Mind to manage challenges.

# 10.1 Theory of change for impact on volunteers: introduction

An overview of the final theory of change related to the impact on volunteers is shown in Figure 10 and Figure 11, followed by a narrative description of these theories and the evidence used to derive them. This chapter draws primarily on interviews with Parents in Mind volunteers, with some additional material from interviews with staff and trainers, and one excerpt from a research memo. One volunteer interviewed left shortly after finishing training because she got a job; all the others interviewed had gone on to actively volunteer.

Most volunteers were very enthusiastic about how participation in Parents in Mind had affected them positively, but they also identified ways in which being a peer support volunteer had been emotionally challenging. These unintended consequences were usually generated by the same peer support activities as the positive outcomes, so in the narrative sections they are presented together. For clarity they have been separated in the two figures below: Figure 10 for the positive theories and Figure 11 for the 'dark logic' of unintended consequences. Mechanisms are shown in two parts: the resources offered (i.e. what happens during Parents in Mind peer training and/or volunteering), and volunteers' reasoning or reaction to these resources. As with outcomes for mothers, all interviewees believed the positives far outweighed the negatives for volunteers.

As described in section 7.4.3.1, the volunteers were demographically diverse across the three sites, and they had a wide range of past and current perinatal mental health experiences. This diversity meant that there were many contextual factors at the individual level. As in Chapter 9, to avoid repetition from earlier chapters and to reflect the emphasis given by interviewees, only individual contextual factors are described here; however it must be remembered that these individual factors also arise within a wider social context. It was not possible to identify specific negative outcomes, beyond a general reduction in emotional wellbeing and/or decision to stop volunteering.



#### Figure 10 Positive context-mechanism-outcome configurations for peer support volunteers

Figure 11 Negative context-mechanism-outcome configurations for peer support volunteers



# 10.2 Positive and negative impacts of being a peer supporter

# 10.2.1 Mental health outcomes

Many of the volunteers said they had underestimated the positive impact that becoming a peer supporter would have on themselves. Some expressed themselves in very strong terms about how it had helped their own mental health (O):

"It's the best thing I've ever done ... It's changed my life. I'm like a different person now at the end of it. Even though I'd got better, I wasn't completely better, but now I know I am." (Olivia(V))

"Parents in Mind has had a massive, amazing effect on me ... As well as helping other people, it's helped me and I feel better about myself. I've managed to come off medication." (Izzy(V))

# 10.2.2 Revisiting own mental health experiences during training

During training, volunteers were expected to share the stories of their own perinatal mental health experiences, and many said that this had stirred up painful emotions, even if their lived experience was many years in the past. However, revisiting these emotions in the supportive environment of training alongside peers had triggered powerful peer support mechanisms among the volunteers, particularly where they had not fully come to terms with their own experiences (C).

# 10.2.2.1 Positive: normalisation

Just like the mothers they would later support, if volunteers had felt ashamed of their feelings (C), they experienced normalisation by discovering that other women had comparable feelings (M), which helped to overcome shame (O) and promote self-acceptance (O):

"You feel, 'I'm terrible at this, but everyone else is Supermum'. You just constantly compare yourself to other people, and when we did the training and I met the other peer supporters, you realise how women all feel the same." (Josie(V))

# 10.2.2.2 Positive: acceptance and understanding

For some volunteers, the training was the first time they had ever had ever spoken openly about their mental health, having hidden their feelings from friends and family (C) because they felt ashamed (C). Feeling understood and accepted by the other volunteers (M), they felt safe to talk honestly about their experiences (M) and experienced emotional release (O):

"We've shared some pretty intense things that we didn't admit to our own family ... It was being in a group with other women and hearing our traumatic stories and crying on each other's shoulders that helped us to turn the training into a therapy session ... It felt like I needed these ladies more than I needed to be a volunteer." (Emilia(V)) Some then also felt able to be more open about their mental health in their social lives (O): *"I hid it very, very well...* [but] *I've now openly said I've had this mental health issue...* [Talking about it at training] *made a huge difference, the fact that I know that it's nothing to be ashamed of"* (Alice(V)).

# 10.2.2.3 Positive: new understanding of past experiences

For several volunteers who had not had not previously received any mental health support (C) or had not previously understood their experiences as perinatal mental health difficulties (C), information gained through training had enabled them to understand and name what had happened (M):

"We relived it, but this time I had friends that I trusted to do it with. I took ownership of it ... You didn't process those emotions at the time, because you were living them. Now you're looking back, and you're working back through it." (Cathy(V))

In some cases this had led to them understanding their experiences more compassionately (O): "I'm less harsh on myself" (Amy(V)), or prompted them to seek professional help (O):

"I found the training really hard because it opened up a lot of things that I hadn't been aware of. It wasn't until we were sitting there talking about psychotic episodes and I thought, 'Oh my God. That happened to me!'... But I've since had counselling ... something I wouldn't have done, if it hadn't been for this group." (Alice(V))

Volunteers who were themselves currently in the perinatal period (C) were particularly likely to experience the information and acceptance gained through peer training as therapeutic for themselves: *"It sounds clichéd, but it has changed my life, literally...I was feeling really, really down ... Once I started doing the course ... beginning to understand yourself, I started to feel better"* (Xami(V)).

# 10.2.2.4 Negative: stirring up emotions with insufficient support

By contrast, Faye(V) felt that there was not enough support to enable volunteers to deal with the difficult emotions that were stirred up by the training (M), and blamed this for the many drop-outs among her cohort (O):

"Every single person that I spoke to said that the training brought up a lot of really painful stuff for them ... I think that the drop-out rate might not have been so high, if there was more personal support during the training." (Faye(V))

Faye(V)'s observation (at site 1) was echoed by some volunteers at site 2, who felt that the way the training was originally delivered had not sufficiently integrated the sharing of personal experience and peer support between volunteers:

"We didn't have very many chances to share what we've gone through because [the trainer] was very structured. It was all about the work. Then at the last session, she said, 'We'll do 10 minutes each and you can tell everyone what you've been through.' And I don't feel like 10 minutes is enough, when someone's been through something so traumatic." (Helena(V))

#### 10.2.3 Social connection

# 10.2.3.1 *Positive: friendships formed*

Many of the volunteers described the training as an intense bonding experience (M), and some said that this had resulted in lasting friendships with other volunteers which increased their social support (O). None of the volunteers described themselves as lacking social support before volunteering, but their peer support friendships had a different quality because - whereas other friends did not understand the mental health experience (C) - these new friends did: *"I've made friends for life from Parents in Mind, closer than friends I've known for years and years, because we've bonded through something that's so close to our heart"* (Olivia(V)).

#### 10.2.3.2 Negative: friendships fading and complicated social dynamics

Some volunteers described how the intense social bond did not last, once the training had finished. They normally volunteered alone or in pairs, and in the context of busy lives had few opportunities to maintain friendships with others who they did not see regularly (M), despite being connected through social media. Several commented that the main attraction of the reflective support sessions was staying in touch with other volunteers: "Just an opportunity for me to see the people that I trained with because I don't get to see them anymore" (Uma(V)). However, others noted that this was of limited benefit, because many volunteers did not attend these sessions: "People just sort of backed away" (Quirat(V)). In addition, the group dynamic of sessions could become difficult, particularly when volunteers had different degrees of 'success' as peer supporters.

"I think some of us are maybe progressing or enjoying it more, and then others aren't, so they don't really want to share or contribute to the conversation as much. So when we come together again, it's quite hard to re-form." (Nina(V))

At site 2, where the initial cohort of volunteers had complex psychological and social needs, relationships conducted through social media had become a source of misunderstanding: *"Worries and whispering and people thinking there's conversations they're not in"* (LPM, site 2). This had had caused some volunteers social stress (O):

"We had a really tight training group, and then we all went out to our separate groups, and it's quite hard to then come back to that tight group again ... You're getting bombarded with social checks and stuff from our WhatsApp group, that isn't to do with the volunteering ... We all have different

triggers, and sometimes that can be a bit overwhelming, or somebody can say something that might be misconstrued." (Mel(V))

# 10.2.4 Increased knowledge and skills

As described in section 7.4.3.4, hopes for personal and career development were part of some volunteers' motivation in joining Parents in Mind, particularly at sites 2 and 3. The training equipped them with knowledge about perinatal mental health, and skills in active listening and basic group hosting. For some volunteers who had left the labour market due to motherhood and had lost confidence in themselves as workers (C), or who were from disadvantaged backgrounds (C), the combination of training and volunteering had a transformative impact on their confidence (M) to the point that they felt able to apply for jobs (O).

"Parents in Mind's had a good effect on me because it gave me the confidence that with everything I've had [including school exclusion and domestic violence], it's time for me to stand up now...The course made me feel I actually could go and get a job...and I've got one!" (Katrin(V))

The local project manager at site 2 observed that the asymmetric nature of the Parents in Mind model was intrinsically beneficial to volunteers' confidence: *"Because the peer support isn't as mutual as some peer support, because they are leading the interaction, that's quite empowering for them – often in their life they haven't got the opportunity to lead."* 

For others who were interested in a change of career (C), volunteering had provided an opportunity to test out a new direction (M) and make a decision to change (O). Some had found work as paid peer supporters in Mother and Baby Units.

"I'm interested in working in mental health. It is something I have been thinking about for years, but I never actually had the confidence to do. But since doing the course, and meeting all the other peer supporters, it's given me the confidence to feel like I can do it now." (Xami(V))

Other volunteers said that learning to be a peer supporter had given them skills that were beneficial for an existing job or other volunteer role (O): *"The listening skills were a wonderful tool to learn ... the exercises have been really instrumental in my work"* (Suzie(V)). These skills could also be applied in personal life to become *"a better person... less judging"* (Mel(V)) (O).

Parents in Mind training was accredited, although not all of the volunteers completed the paperwork needed for the qualification to be granted. Two of the trainers said that for volunteers who had low levels of educational attainment (C), success in gaining the qualification (M) could be significant boost to their self-efficacy as learners (O), as well as relevant to their employment prospects (O). "Three of the peer supporters have gone on to get jobs directly in this field and for them, an accredited qualification is important... We have some mothers who have no qualifications at all... For me to give [a volunteer] that certificate with her name on it, and this was the first award she'd ever had for anything, that is really powerful... It opens their doors to the feeling of 'You know what, I <u>can</u> do education!'" (trainer, site 2)

# 10.2.5 Making a difference

# 10.2.5.1 *Positive: feeling successful at making a difference*

As described in section 7.4.3.4, the majority of volunteers had altruistic motivations for their involvement in Parents in Mind (C). Volunteers talked passionately about the satisfaction (O) they derived from knowing they were successfully making a difference to mothers (M), either because they saw mothers' mental health improving or through mothers' feedback. It was their own peer experiences that gave this mechanism such force: as helper-therapy it could improve their self-esteem (O) and give a retrospective meaning to their own mental health difficulties (O):

"I had a good eight years feeling the worst I could ever feel. I was suicidal. I was self-harming. I would never, ever want to see a mum in that situation and not be getting any help. Knowing I'm making a difference for mums ... is everything to me." (Izzy(V))

# 10.2.5.2 Negative: guilt and worry if mothers disengage or don't get better

It took considerable emotional resilience for volunteers to cope with the situation where they could <u>not</u> be sure that they were making a difference to mothers with whose suffering they profoundly empathised as peers (C). Where mothers did not show any discernible improvement in mental health, or disengaged from the peer support without explanation, volunteers sometimes blamed themselves (M) and reacted with feelings of sadness and guilt (M).

"One mother left, and we never knew if anything we had done for her was okay. ...It took us a while to let go, because we carried some guilt and we were asking each other, did we honestly think that we had done or said anything to put her off?" (Emilia(V))

If a mother decided to discontinue one-to-one sessions with a volunteer, there was a risk that this could feel like a personal rejection as well as failure (M). One local project manager described a situation where she had intervened to protect the volunteer from self-recrimination: *"It was tricky handling it, because the volunteer had low self-esteem, so I let [the mother] leave the service and [the volunteer] thinks it's because she went back to work"* (LPM, site 3).

The volunteer training made it clear that *"we're not there to fix them"* (Mel(V)), but there was a temptation to hope that this was exactly what would happen, as described by Suzie(V): *"Sometimes when you meet people and they're vulnerable and you really want to help them, you can go right into* 

*fixer mode, 'I am going to fix this.'"* Staff had noticed that where mothers with more serious or entrenched mental health difficulties (C) attended peer support for a long time without discernible change, this could be difficult for volunteers who were disappointed in their hope for a positive trajectory (M):

*"We're not here to fix anybody, but equally the volunteers <u>want</u> to feel like they've fixed somebody, and when you're welcoming all and sundry in, with longstanding, far-reaching issues, these are not going to be impacted upon by eight sessions of one-to-one in a peer relationship."* (LPM site 2)

Some volunteers talked about the problem of 'not making a difference' in terms of the intrinsic limitations of peer support as a response to people in mental distress. They could feel frustrated, guilty and sad (M) when they recognised that a mother needed more than the volunteers could offer (C): *"How do I give you coping strategies, because the only coping strategies I've got are personal to me, so I just didn't know what to say"* (Quirat(V)). They might both accept the reasons for the boundaries of peer support, and chafe against or even subvert those boundaries:

"Some mums expect to receive more support ... I know my limit but sometimes it really annoys me that I have this limit, and I would like to have more skills to provide support ... And this feeling sometimes of helplessness, I wish I could use a specific technique to make them see other sides of things or to get deeper into their worries ... I don't always do only listening. On a few occasions, I actually did my own research ... and I gave them some material to read, something that I had received, for example from Talking Therapy." (Wanda(V))

Paradoxically, where volunteers felt they <u>were</u> making a difference this could become a further source of guilt when their support was only available at limited times (M):

"At the beginning of the summer holidays we saw clearly that the mum who was coming to see us looked lost and she was going to miss coming to see us ... It was difficult to say, 'They have to deal with it somehow, and when we are back we are back."" (Emilia(V))

Many volunteers described the emotional complexity of building relationships while maintaining peer support boundaries. They genuinely cared about the mothers (C) and worried about the wellbeing of those who did not attend (M), but were not allowed to be in contact with them outside the peer support sessions. Volunteers' uncertainty about what happened next to mothers who stopped attending (M), particularly if they appeared to have high mental health needs, could be another source of stress.

"It's a different kind of relationship which I've never really had before. Because if it was a friend you'd talk as a friend. Then you would be contacting them to make sure they're all right. Whereas we obviously cannot contact them ...You care about them and want to help them." (Helena(V))

It was hypothesised in the initial theory of change that volunteers would build a close emotional bond with mothers during one-to-one peer support and would feel sad at the ending of these relationships. However, as for mothers (reported in section 9.3.8.3), there was no evidence from volunteers that they felt distress about the ending of these relationships where they had gone well.

#### 10.2.5.3 Negative: worry about making things worse

Many volunteers described feeling worried and stressed that they might inadvertently say or do something that would undermine a mother's mental health (M), particularly if the mother had more serious mental health difficulties (C) and when the volunteers were inexperienced (C).

"As a peer supporter you're scared at first ... When someone comes in and they're really hurting, they've really got deep issues, you're frightened almost to speak to them, because you don't want to say the wrong thing. You don't want to make them feel something that they then go away and are just left to deal with on their own, because then you would feel really guilty about that." (Vani(V))

Izzy(V) felt unable to cope with the stress of an incident where she was concerned she might have said something wrong, combined with pressures in her home life. This had led her to stop volunteering, although she had hoped this would be temporary: *"I'm a little bit nervy. I just need to build me confidence up again."* 

Volunteers were most likely to have these anxieties if they lacked self-confidence (C); but many also said they did not feel that the training had fully prepared them for the role (C).

"Some people have a bad week and they're obviously upset. You come away thinking, 'Did I do the right thing? Did I say something that's then caused that?'... It's maybe me and a confidence thing, doubting everything and questioning everything." (Helena(V))

"The training was a bit ad-hoc ... Some of the women that we're meeting, their needs are more complex and we hadn't really looked at that. So the trough [as a volunteer] has been putting it into practice and wondering actually, am I trained enough to do this?" (Uma(V))

Some volunteers observed that it was probably impossible for training to fully prepare a person in advance for becoming a peer supporter, but their confidence and skills had grown with practice: *"When you start doing it, it's a completely different ballgame, it's not textbook stuff"* (Ginny(V)). Some volunteers described how they had buffered the confidence gap with skills and confidence drawn from previous experience, including nursing, counselling, doula work, and breastfeeding peer

support: "Having all my other training from college really, really helped me. If I hadn't have had that, I probably would have freaked out." (Izzy(V))

Staff described volunteers with relevant professional experience as a crucial asset to Parents in Mind. They were paired with less experienced volunteers at peer support groups to enable them to model effective facilitation skills.

# 10.2.5.4 Negative: disappointment if mothers do not attend

It could be challenging for volunteers to remain motivated, particularly in the early months of the programme when there were few mothers to support, and groups were so quiet that sometimes no one attended. Volunteers expressed a mixture of frustration and sadness that they were not reaching mothers in need (M), sharpened by their empathy and altruistic motivation (C).

"There's a lot of people out there who desperately need help ... Doctors are all too easy to give you a prescription and say, 'Take these anti-depressants', when so many more people could be sent to our groups ... I get a bit frustrated that doesn't happen." (Ginny(V))

Morale could also be affected if mothers who had (in principle) taken up the offer of peer support did not attend one-to-one appointments or groups. This could make some volunteers feel that their time and effort was wasted or not appreciated (M). None of the volunteers interviewed had left the programme as a result of demotivation, but it is possible that this contributed to others leaving the programme (O):

"The most disgruntled that my volunteers have ever been is when they've come out for a one-to-one – some have travelled a long distance to offer support – and they sit there for an hour not notified that mum is not coming... it feels personal". (LPM site 2)

By contrast, some volunteers were able to draw on their own mental health experiences to understand non-attendance compassionately, and to frame their contribution as the <u>offer</u> of peer support, whether or not a mother chose to make use of it.

"Sometimes when nobody's turned up, some people have had a bit of a moan and complained that they're wasting their time... but we have to remember how rough we felt when we were in that situation, and that maybe going and meeting someone is the last thing that [the mothers] feel up to doing, but still be there in case they feel up to it the next week." (Nina(V))

# 10.2.6 Feeling emotionally 'triggered'

Peer experiences enabled volunteers to empathise with mothers' mental distress, but strong empathy (C) also created challenges in managing their own emotional responses to disclosures (M).

Some had felt emotionally triggered by specific situations they had encountered which reminded them closely of their own experiences (M).

"I did the one-to-ones for a while, but I had a pretty tough run with a mum ... [She] just seemed to need a lot more than what I could give, and then it came to a head when she was telling me that she'd spent the weekend not wanting to live anymore... It did bring back a lot of stuff for me." (Laura(V))

Occasionally this distress had meant that the volunteer was unable to continue to support that mother, for example Quirat(V) withdrew from a one-to-one: *"I really felt bad for her because she really does need help, but then I had to say that I can't be that person, it was just too hard."* Other volunteers said that they were able to deal with the feelings when they were emotionally triggered, suggesting personal contextual factors of resilience and coping strategies (C):

"When we talk about triggers, I guess there are elements where it might bring a tear to my eye or I might feel a bit sick at the thought of what we're talking about, but not to a point that it's not manageable." (Nina(V))

Where the local project managers were aware of all the circumstances, they could protect the volunteers by giving them the option not to do one-to-one support with a mother if there were similarities that could be uncomfortable:

"We did have a lady that came in with PTSD, because of [a specific situation] and [the local project manager] was very keen to make sure that I was going to be alright with it .... I felt supported, and because I felt supported, I was more than happy to support the lady." (Alice(V))

Tanya(V) believed that the interview with the clinical supporter during training was another important safety mechanism in enabling volunteers to be aware of potential triggers and their ability to deal with these: *"Some people might not even know themselves how much they can manage or not, and I think [the clinical supporter] gives a good insight on that."* 

# 10.2.7 Impact on volunteers of not sharing their personal experience

Chapter 9 highlighted the ways in which peers talking about their own lived experience was essential to many of the mechanisms of peer support, and the disruption to these mechanisms when volunteers felt inhibited from sharing because of the emphasis in the original training (see section 7.5.10). This inhibition also had an impact on the volunteers. Some said that they found it both stressful and impractical when trying to offer peer support to mothers who were reaching out for emotional connection, experiential knowledge and social comparison: *"That's the most difficult part*"

of the conversations ... you want to be able to empathise and let people know that they're not alone." (Suzie(V)). If they broke the 'do not share' rule, they worried about having done something wrong:

"[This mother] was desperate for us to say, 'This is what happened to us, and look at us now. We all came through it'. She specifically asked us. The training taught, that was very much the thing that we weren't to do ... Myself and my co-worker came out saying, 'Oh dear, we've said a bit more than we should've done', because you felt like, how could you not? It would be like pushing her away." (Deborah(V))

When the programme's position on sharing lived experience was clarified, this stress was resolved, so it has not been included in the theory of change: *"The people who were doing it secretly, or felt they shouldn't be doing it ... they've all said 'It's <u>so much easier to offer support because I can actually talk to the person!"* (LPM site 2)</u>

# **10.3 Volunteers' experiences of support to manage challenges**

# **10.3.1 Positive experiences of support**

The structures created to mitigate the risk of psychological harm have been described in Chapter 7. Volunteers who had experienced distress as a result of their volunteering generally spoke warmly of the support that enabled them to manage their emotional reactions: *"Our own mental health is looked after very well alongside volunteering"* (Olivia(V)).

#### 10.3.1.1 Support from other volunteers, staff and clinical supporter

Volunteers identified three key sources of support. The first of these was emotional support from other volunteers: *"I know if I'm having a bad day, I can just phone one of the girls and they'll be there to talk. And if any one of them girls phones me, I would sit the whole day and speak to them"* (Izzy(V)).

The second source of support was affirmation and emotional support from the local project managers. At all three sites, volunteers appreciated how their wellbeing was 'held' by the local project managers: *"We've been supported very closely, kindly and sensitively ... [the local project manager] is absolutely wonderful, she's there if you need her, and we've always known that"* (Deborah(V)). Many mentioned specific incidents during volunteering that they had taken to the local project manager for a second opinion: *"One session I felt like I was failing as a peer supporter... [local project manager] is always very supportive"* (Wanda(V)). Some volunteers described how their relationship with staff was one of the main things that kept them motivated: *"Sometimes you can lose that sense of, 'OK why am I doing this?' The thing that reinvigorated me recently is when I went to see [the local project manager] and [trainer], I feel a closeness to them"* (Uma(V)).

The third source of support was the possibility of a more formal therapeutic conversation with the clinical supporter. Few volunteers spontaneously made use of this, as most found the local project manager gave them all the support they needed. Those who used the clinical support said they had found it valuable, and others appreciated that it was there as a back-up: *"Having that net to catch us if we feel vulnerable is like a safety net in itself, just knowing that it's there"* (Mel(V)).

# 10.3.1.2 *Reflective group support*

Because the peer support was carried out individually, or in pairs or small groups, some volunteers felt that coming together with (in theory) the whole team at the reflective sessions had a wider value of helping them feel connected to Parents in Mind: *"You don't feel you're just doing it in isolation; you feel you're part of a much bigger picture"* (Deborah(V)). A few said that they found the sessions useful to continue building their confidence and skills, as well as learning from other volunteers' experiences: *"I like to hear about what situations have arisen ... maybe they've offered some really good help, or maybe something bad's happened, and we can discuss it and say what we would do."* (Mel(V)). Others said that the regular social support at these sessions was essential to maintain their motivation as volunteers: *"Being there with the other ladies reinforces our commitment, and without seeing each other on a monthly basis, I think I would not do it"* Emilia(V).

# 10.3.2 Negative experiences of support

# 10.3.2.1 Support from other volunteers, staff and clinical supporter

A couple of volunteers said they did not find the support available from the programme useful, and had functional rather than warm relationships with their local project managers. For example, Quirat(V) did not feel that she could get meaningful emotional support within Parents in Mind:

"I've turned to friends rather than turning to the project for support... I don't think that I bonded with [the clinical supporter], so I don't feel comfortable going to her and saying how I feel. I feel OK talking to [the local project manager] but then I feel she always looks at it from a project point of view, so then I just go to my friend."

Likewise Faye avoided the question when asked about her relationship with the local project manager, as noted in a reflective memo after the interview: *"Unlike other volunteers, there was no warmth in her voice when referring to [the local project manager]. She did not answer the question, but said flatly that she had contacted the LPM once about 'a client'. She has extensive experience as a volunteer elsewhere and may be inwardly making a comparison?"* 

The stresses that could arise in relationships between volunteers have been described in section 10.2.3.2.
#### 10.3.2.2 Reflective group support

Reflective support sessions were consistently poorly attended. Many volunteers said this was because the sessions clashed with their working days or they did not have childcare, but in the early months of the pilot there were also specific complaints about the way these groups were run. In particular, volunteers were frustrated that most of the time was allocated to the trainers to complete the accreditation paperwork or repeat messages from the initial training.

"We thought those sessions would be an opportunity for us to talk, but they were taken over by [the trainer] ... Every time we go, she talks about the workbooks. One of the girls had gotten very ill. She wanted to talk, and we wanted to give her time to talk. [The trainer] was like, 'We've no time.'" (Nina(V))

At site 2, this approach crowded out peer support among the volunteers and reflection on issues arising from their volunteering, leading the local project manager to become concerned that she would lose her volunteers:

"I don't want them to be plonked down, talked at for two hours and then go – that will have an effect on how long they volunteer for ... It's absolutely key to retention that the reflective stuff is informal and a chance to reengage with people you've trained with."

At site 1, there were complaints that the clinical supporter did not focus on the volunteers' own support needs when leading the reflective sessions, and at site 3, there were complaints that the sessions were being used to talk about service development rather than volunteer welfare.

"The reflective practice [is apparently] not for us to talk as peer supporters about how we're feeling... It just seems to be how we're going to move the group forward, or how we're going to get more people to come in. And so I don't find it as beneficial, to me as an individual, as I thought." (Vani(V))

In response to feedback from the volunteers, the format of the groups was changed so that by the end of the pilot they were mainly led by the local project managers and focused on mutual support and reflection on issues that arose during volunteering. Xami(V) experienced reflective support after these issues had been addressed, and appreciated it: *"They're really great for when we have questions, when we just need a bit of reassurance... you get that little bit of a boost every once in a while, just to reflect."* 

# 10.4 Comparison between initial theory of change and final theory of change

The final theory of change for Parents in Mind included eight positive C-M-O configurations and seven negative C-M-O configurations relating to the impact of peer support on volunteers. In Table 24, the final theory of change is compared to the hypotheses of the initial theory of change. All of the differences between the initial and final theory of change related to mechanisms, so to avoid duplication, only mechanisms are presented here, without their associated contexts and outcomes which appear throughout this chapter and in Figure 10 and Figure 11.

N	Initial theory of	Final theory of	
Resource – What happens at peer support training or volunteering	Volunteer's reaction or reasoning	change	change
Revisits own mental health experiences in supportive peer	Realises others feel the same, feels normal	x	1
context	Feels accepted and understood, can speak openly	x	1
Revisits own mental health experiences but not enough support	Cannot cope with emotions that have been stirred up	x	1
Information shared about perinatal mental health conditions	Applies information to understand or reinterpret own experiences	x	1
Sharing stories creates intense bond	Makes new friends who fully understand	1	1
Social bonds with volunteers not maintained	Disappointment, social stress	x	1
Misunderstandings undermine relationships within group		x	1
Gains knowledge, skills and experience	Increased self-confidence, understanding of mental health support	1	1
Achieves accredited qualification	work, realises skills transferable to other work or relationships	1	1
Sees mothers' mental health improving or mothers express gratitude	Feels successful at making a difference (helper-therapy)	1	
Able to use her story to help others	Positive reframing of the meaning of her experiences	1	1
Mothers disengage or don't get better	Self-blame, guilt, worry, sadness Frustration at limitations of peer support	1	1
Mothers' needs exceed peer supporters' skills	Worry and stress about making things worse	x	1
Mothers don't take up peer support or don't attend meetings	Sadness, frustration, feels under-valued and rejected, demotivation	1	1
Mothers talks about their experiences	Feels emotionally 'triggered'	1	1
Volunteer makes close emotional bond in 1:1 support	Sadness at ending of 1:1 relationship	1	x

#### Table 24 Comparison between initial and final theory of change for volunteers

#### Key

Positive mechanism	Italics:	Mechanisms that were in the final but not the initial theory of change
Negative mechanism	Strikethrough:	Mechanisms that were in the initial but not the final theory of change

## **10.5 Chapter summary**

This chapter has explored the complexity of the programme theories operating within the change model for volunteers. Peer support mechanisms, including normalisation and acceptance, could be activated between volunteers during the training. The training gave them a new understanding of past experiences, increased social support, and increased skills and confidence, which could in turn have a positive impact on their personal and professional lives. Active volunteering offered opportunities for helper-therapy when volunteers could see that they were making a difference to the mothers. At the same time, there were psychological challenges for the volunteers, primarily from the volunteering rather than the training. These included self-blame, guilt, worry, and sadness if they felt they were not helping mothers adequately or were potentially making things worse; feeling 'triggered' by mothers' experiences; frustration at the limitations of peer support; distress at not knowing what became of mothers who left the peer support unexpectedly; and social stress from complexities in relationships with other volunteers. Precisely because they had experience of perinatal mental health difficulties, volunteers were particularly vulnerable to distress, and needed significant support from within Parents in Mind to deal with these challenges. Volunteers felt that the positive impacts of their role far outweighed the negatives.

The next chapter is a discussion of the results of the primary research and realist review in the context of the wider literature.

# **11 Discussion and Conclusions**

## **Chapter overview**

This chapter begins with a summary of the evaluation findings, which are compared with the findings of the realist review and wider literature. It discusses the complex findings on normalisation and on who is a peer, and then considers issues connected to running a peer support programme: the format of support; the recruitment, training and support for volunteers; the relationship between peer support and professional support; and the challenges of measuring recovery outcomes. Finally it describes the contribution to knowledge made by this evaluation, its strengths and limitations, and the implications for practice and research.

## **11.1 Summary of findings**

The evaluation of Parents in Mind has shown the value and complexity of third sector perinatal mental health peer support. It has demonstrated how trained volunteers can give one-to-one support and facilitate groups wherein multiple mechanisms can lead to individually meaningful improvements in a mother's emotional and psychological wellbeing and wider participation in society; and how volunteers also benefit. It has also illustrated the potential for unintended consequences: the purpose of highlighting these is so that they can be mitigated in the design of future programmes (Bonell et al., 2015). All interviewees believed the positive aspects of peer support far outweighed the negatives for both mothers and volunteers.

#### 11.1.1 Implementation

#### 11.1.1.1 Overall implementation

During the pilot, 77 volunteer peer supporters were trained to give support and 182 of the 260 mothers referred received support, representing 70% take-up. Three-quarters of mothers were White British, three-fifths were first time parents, and nearly half were socio-economically deprived. Three-quarters had a previous history of mental health difficulties, and half were in touch with the perinatal mental health team. Using the Hospital Anxiety and Depressions Scale (HADS), baseline median scores indicated mild depression and moderate anxiety, but a third of mothers had scores indicating severe anxiety. There were many adaptations made to improve the programme during the pilot, including widening the criteria for who could take part.

#### 11.1.1.2 Differences between sites – contextual learning about take-up

The opportunity to carry out a process evaluation at three sites generated rich insights about how local contextual factors could affect take-up of peer support. At site 1, mothers who took up support were more socio-economically advantaged than at other sites. There was a strong perinatal mental

health infrastructure, and referral and take-up became robust by the end of the pilot, although Parents in Mind did not break through to the local Asian communities. At site 2, where there were poor transport links and maternity care was divided between four hospitals, referral and take-up was slow but steady by the end of the pilot. Mothers who took up support were mainly very socioeconomically disadvantaged, reflecting the local population. At site 3, referrals were much lower than hoped and the site had the lowest take-up. The majority of mothers who used support at least once were socio-economically disadvantaged and nearly half were from Black, Asian and other minority ethnic backgrounds, but it was generally the more advantaged White British mothers who continued attending.

The experience across all three sites highlights the importance of understanding the local context, and also what local mothers want and need, before establishing a peer support programme. At the end of the pilot, continuation funding had been secured at sites 1 and 2. At site 3, instead of continuing Parents in Mind, NCT joined a partnership of community organisations with a new service (Newham Nurture) for pregnant women and mothers from migrant communities and/or those experiencing socio-economic disadvantage, offering pregnancy information sessions, drop-in groups, counselling, and one-to-one social, emotional and practical peer support (NCT, undated). This is in line with research suggesting that volunteer support programmes not focused on mental health, or which have a more practical remit, can successfully support mothers from Black and Asian and other minority ethnic communities and those living with multiple disadvantage, and can have a positive impact on their self-reported emotional wellbeing (Lederer, 2009; McLeish & Redshaw, 2017b).

#### 11.1.2 Social and individual contexts and mechanisms related to take-up

There were 16 theories linking contextual factors to mothers' individual choices to make use of Parents in Mind. At the macro-level, these contextual factors included social values and norms about motherhood and mental health. At a meso-level these were factors related to the local health system. At a micro-level there were three groups: one related to the mother's beliefs about mental health and her reactions to social attitudes; the second related to her mental health and experiences of professional support; and the third related to other individual factors such as feeling comfortable with people from a similar background, and having the resources of time, money or language to make use of peer support.

One group of mechanisms leading to take-up concerned the mother's beliefs about peer support itself; a second group concerned social expectations; a third group concerned her relationship with health and social care professionals and mental health services; a fourth group was about practical benefits; and finally there was a group of mechanisms which could be framed as 'overcoming barriers', such as being able to use peer support in ways that did not exceed her resources.

Out of all of these theories with the outcome of a mother taking up peer support, the foundational context would appear to be the mother's belief – which might be influenced by cultural background – that it is helpful and acceptable to talk to others about one's feelings. The other clusters of theories relate to why a mother might choose to talk to a peer (as opposed to, or in addition to, family, friends or a mental health professional), and how she could be enabled to access peer support, but these were irrelevant if the mother did not share this foundational belief that 'it's good to talk'. The exception was mothers who did not necessarily want to speak about themselves, but wanted to gain access to normalisation and hope by listening to other mothers' stories.

## 11.1.3 Contexts and mechanisms leading to impact on mothers

Mothers came to Parents in Mind with a range of mental health difficulties (both self-defined and diagnosed). They engaged with peer support for widely varying periods of time, had different preferences for group or one-to-one support, and later described a range of benefits they got from the peer support. There were 16 positive C-M-O configurations and 12 negative C-M-O configurations relating to the impact of peer support on mothers.

Parents in Mind peer support consisted of a variety of interlocking activities, contributing to mechanisms which provided empirical evidence for the middle range theories discussed in the realist review (Chapter 4):

- Non-judgemental, empathetic, confidential active listening by peers could make a mother feel understood, accepted and able to speak about her experiences, as predicted by theories of emotional social support and emotion-focused coping assistance (Cohen & Wills, 1985; House, 1981); self-disclosure (Rogers, 1956); and experiential knowledge (Borkman, 1976).
- Positive feedback could make her feel affirmed and encouraged, as predicted by theories of appraisal social support and perception-focused coping assistance (Cohen & Wills, 1985; House, 1981); and overcoming stigma (Goffman, 1963).
- Hearing peers talking about their own experience of mental health and parenthood could normalise her experiences and enable her to realise that others have recovered or had greater problems, as predicted by theories of social comparison (Festinger, 1954); groups as normative narrative communities (Rappaport, 1994); social learning (Bandura, 1977); overcoming stigma (Goffman, 1963); self-compassion (Neff, 2003); and experiential expertise (Borkman, 1976).
- Hearing peers sharing non-directive ideas about self-care and parenting could give her new strategies and the motivation to try them, and signposting to community services could give her information and motivation to try them, as predicted by theories of informational social

support and problem-focused coping assistance (Cohen & Wills, 1985; House, 1981); experiential knowledge (Borkman, 1976); and social learning (Bandura, 1977).

- When peers used therapeutic techniques such as reframing and encouraging small steps, this could give her different ways to see situations and small mastery experiences as predicted by the theory of perception-focused coping assistance (Cohen & Wills, 1985).
- Being able to help others at a group could bring satisfaction and a sense of meaning, as predicted by the theory of helper-therapy (Riessman, 1965).

In addition mothers could benefit from the dynamics that could develop through regular group attendance, such as the opportunity to make friends and the routine of regular meetings; and also believing that the volunteers cared about those they supported.

These mechanisms could be triggered by different contexts at the micro-level: the mother's reactions to social attitudes about mental health; issues related to her personality and mental health; and other personal factors such as her knowledge of local services, the chaos of life with a baby, and social isolation. Not all programme theories applied to each mother supported, because mothers differed in their backgrounds, personalities, social situations, resources, experiences, beliefs, and needs. For example, some mothers primarily wanted to talk about themselves, and found it boring to listen to others describing their problems; while other mothers did not want to talk about themselves, but wanted to listen to others. Equally a mother might benefit from suggestions about coping with mental health and parenting if she saw peers as a credible source of information, even if she did not feel particularly stigmatised by her perinatal mental health difficulties.

Some of the negative mechanisms occurred when the peer support activities were absent - for example, the mother did not feel she was listened to; she was influenced by unhelpful directive advice from others in the group; she was frustrated that peers withheld information about their own experience; she was encouraged to focus on negativity; and attempts at friendship failed. Other negative mechanisms occurred in response to the same activities as those that triggered positive responses from mothers, where there were different individual contextual factors at work – for example, peers listening could feel like pressure to talk; peers talking about themselves in a group could make the mother feel that she didn't belong, that others were making faster progress or that others had greater problems; routine could make peer support feel like a social obligation; and the fact that peer supporters were volunteers could make sessions unreliable. These negative mechanisms highlight the importance of skilled and knowledgeable facilitation of peer support groups.

#### **11.1.4 Outcomes for mothers**

There were many positive proximate outcomes from peer support, affecting mothers' emotions, thoughts and behaviours, depending on the mechanisms activated. Talking openly led to emotional release; acceptance by others led to self-acceptance; positive feedback and gaining new ways to see situations generated self-confidence and self-esteem; normalisation helped to overcome shame; upward social comparison engendered hope for recovery; downward social comparison enabled mothers to put their own difficulties in perspective; gaining credible information could increase parenting confidence, coping strategies and the use of appropriate support; the opportunity to help other mothers could give a sense of satisfaction and meaning; making new friends reduced loneliness; gaining structure to the week enabled mothers to feel more in control; and believing that peers cared about her made a mother feel cherished.

There were also more limited potential negative outcomes, also depending on the mechanisms activated. If mothers felt unable to talk openly, they were denied emotional release. If they did not identify with the peers, they continued to feel abnormal. Lateral social comparison could make them feel discouraged about recovery. Upward social comparison could make them feel self-critical, and downwards social comparison could make them feel weak and judged. Being influenced by inappropriate advice could lead to disappointment if the advice did not work, or to loss of confidence in mental health services. On the other hand, if mothers genuinely wanted advice, not receiving it led to disappointment and frustration. If the group focused on negative feelings, the negative perception of motherhood was reinforced. Lack of success at making friends could create feelings of social failure. If peer support became an obligation, they could become self-critical for letting people down. If peer support was not dependable, mothers could experience difficulty coping.

During the time that mothers used peer support, there was a statistically significant reduction in median anxiety and depression scores as measured by HADS. Median anxiety scores reduced from moderate to mild, and median depression scores reduced from mild to normal. Two-thirds of mothers had lower anxiety and depression scores after peer support. The before/after methodology used in the evaluation does not allow direct claims about causation to be made on the basis of these figures, which may have been affected by other factors such as the use of therapy (for 18% of mothers) and medication (for 21% of mothers), life events, and the tendency of perinatal mental health difficulties to resolve spontaneously for up to 40% of mothers (Dennis et al., 2012).

These results are, nonetheless, in line with the findings from RCTs of one-to-one and group peer support for mental health difficulties, which have found statistically significant reductions in depression scores and non-significant reductions in anxiety scores (Chen et al., 2000; Dennis et al., 2009; Shorey et al., 2019) (see Chapter 5). There was evidence that many mothers *believed* that

Parents in Mind peer support was responsible for their improved mood; and where their overall mood had not improved or had deteriorated, they *credited* peer support with helping them to cope better and to have a better quality of life, consistent with the concept of recovery 'within' mental health difficulties (Davidson & Roe, 2007; Leamy et al., 2011), which is not captured by traditional clinical measures (Andresen et al., 2010). There was some evidence that peer support was more likely to have an impact on anxiety and depression scores as measured by HADS for mothers with milder and more transient mental health difficulties, whereas an impact on subjective wellbeing was reported by mothers with more serious or longstanding difficulties.

#### 11.1.5 Contexts, mechanisms and outcomes for volunteers

There were eight positive C-M-O configurations and seven negative C-M-O configurations relating to the impact of peer support on volunteers, connected to training, volunteering or both. If the volunteers had unresolved emotions, then training offered them their own experience of peer support, leading to outcomes such as self-acceptance and emotional release. If they did not have friends who understood their perinatal mental health difficulties, then sharing stories at training could create an intense bond and lead to new friendships. During training they also received information which enabled them to understand or reinterpret their own experiences, and this could lead to gaining perspective, self-compassion, and a decision to seek psychological therapy. If they had low self-confidence and limited education, the skills and knowledge developed through training and volunteering increased their self-confidence and led to new employment opportunities and life skills. Altruistic motivations led to experiencing satisfaction at helping others when they felt successful at making a difference to mothers' mental health.

There were three groups of negative programme theories for volunteers. The first related to volunteers' mental health experiences: if they had unresolved emotions and strong empathy they could feel emotionally 'triggered' if there was ineffective support at the training, or by hearing a mother's distressing experiences during peer support. The second related to the social dynamics within the volunteer group which could be stressful, particularly if they had little time to invest in relationships or had complex psychological needs. The third related to experiences of support appearing not to 'work', which was challenging for volunteers who had strong empathy, altruistic motivations and limited resilience. It was not possible to identify specific outcomes from these mechanisms beyond a general sense that they would lead to reduced emotional wellbeing and might cause a volunteer to leave her peer support role.

## **11.2 Comparison with realist review literature**

#### 11.2.1 Evidencing theories fully

Iteration between the realist review and primary research meant that, inevitably, there was considerable overlap between the two theoretical models (initial and final) for the review and the two theories of change (initial and final) for Parents in Mind. In the realist review, the non-realist empirical studies provided evidence for contexts, mechanisms and outcomes but these were not necessarily connected. The in-depth interviews for Parents in Mind provided an opportunity to fully explore and evidence C-M-O configurations, and in particular to fill in the gaps where the theoretical links between contexts, mechanisms and outcomes were only hypothesised in the realist review.

#### 11.2.2 **Differences in intervention and population**

There were some key differences between the review interventions and the primary research. Unlike any of the review interventions, Parents in Mind offered a choice of one-to-one or group support. It did not offer telephone support, which was the only type offered by seven review interventions. Whereas six of the review interventions specifically excluded mothers with a previous history of mental health difficulties, the majority of mothers in Parents in Mind had such a history. In eight of the ten review interventions that reported social class or education, over two-thirds of mothers were from advantaged socio-economic groups and/or had post-secondary education; whereas in Parents in Mind, over two-thirds of mothers at sites 2 and 3 were socio-economically disadvantaged.

#### 11.2.3 Different findings on C-M-O configurations connected to take-up

In addition to C-M-O configurations related to the particular format of Parents in Mind, there were some general programme theories which had not been identified in the realist review. Motivations for taking up peer support included actively seeking out upward social comparison to gain role models for recovery, hoping to make friends, looking for ways to structure their time with a young baby and a reason to leave the house. There was also evidence highlighting the importance of a mother's ability to make autonomous decisions to attend, without the intervention of family gatekeepers.

#### 11.2.4 Different findings on C-M-O configurations connected to impact on mothers

In contrast to the findings of the realist review, some mothers using Parents in Mind went on to talk about their feelings to family and friends as a direct result of 'practising' disclosure and growing in self-acceptance. Some of the peer supporters had successfully used therapeutic techniques, such as reframing and enabling mothers to build their confidence through small mastery experiences.

Some negative C-M-O configurations in the realist review were not found in Parents in Mind: normalisation feeling like minimisation of problems, and feelings of loss at the ending of support.

This latter was present to a small extent in Parents in Mind in the first pilot year, but not in the final model; this may reflect the fact that most mothers left peer support when they felt ready, or that they successfully maintained social relationships outside the peer support group. Some negative C-M-O configurations that were not identified in the realist review were present in Parents in Mind: the failure of attempts at friendship leading to a loss of social confidence; peers sharing unhelpful or directive ideas about perinatal mental health treatments in groups; and postnatal mothers self-censoring to protect the wellbeing of pregnant women at a group.

#### **11.3 Comparison with literature on the impact on peer supporters and volunteers**

Most of the positive programme theories for Parents in Mind volunteers indicate similar benefits to those reported for mental health peer supporters outside the perinatal period and volunteers giving perinatal support not focused on mental health (summarised in section 1.2.9), but add ontological depth through C-M-O linkage. They also reflect the benefits to peer volunteers reported, in limited depth, in two studies on postnatal depression in the realist review: self-acceptance, realising how far they had come, and finding closure (Carter et al., 2018); or personal healing, knowledge, social integration and raised self-esteem from making a difference (Dennis, 2013). A distinctive finding was that for some Parents in Mind volunteers with unresolved emotions, taking part in the volunteer training triggered powerful peer support mechanisms for themselves.

The Parents in Mind findings also reflect the challenges for peer volunteers reported in the context of postnatal depression: feeling guilty that the ending of the support after a fixed number of sessions might make a mother's depression worse (Carter et al., 2018); or worrying that the support they provided was not useful or not sufficient, and feeling disappointed if the mother did not engage (Dennis, 2013). Responding to this latter point, the training for the Canadian telephone peer support trial was adapted to warn volunteers that this could happen and to encourage them not to take it personally (Dennis, 2014a). There were some additional difficulties identified for Parents in Mind volunteers: finding that the training stirred up emotions that they could not cope with, and disappointment and social stress when positive relationships with other volunteers were not maintained. Unlike some other studies (e.g. Dennis, 2013; Spiby et al., 2016), Parents in Mind volunteers did not report feelings of friendship towards the mothers they supported, so their distress when mothers dropped out of support was based on concern for their wellbeing, not the loss of relationships. This may be because much of their support was given in group settings, and there were contrasting views on the importance of individual relationships (see section 11.6.1).

Most of the challenges for Parents in Mind volunteers have also been identified in other peer support scenarios, including the complexity of sharing lived experience appropriately: "how to keep to the principle of 'I am here to tell you what my life was like but not to tell you how to run your life...or to compare mine to yours'" (Moran et al., 2013, p. 287). In a realist review of peer support for breastfeeding, Trickey et al. (2018) noted that because peer volunteers felt demotivated if mothers did not appear to appreciate their support, there was a tendency for peers to focus their support on those who were easiest to help because they were more committed to breastfeeding. While Parents in Mind volunteers also experienced stress when their support did not appear to 'work' for a mother, the programme as a whole went in the opposite direction to the breastfeeding peer support programmes, by choosing to expand their offer to include mothers who had more serious or chronic mental health difficulties and were <u>less</u> likely to provide a 'happy ending'. Staff understood that this was more challenging for their volunteers, but believed this could be managed through effective support for the volunteers to understand that they could make a difference even if the outcome was not recovery 'from' mental health difficulties.

## 11.4 Peer support and 'normalisation'

The term 'normalisation' is often used in connection with peer support, but this research has found some interesting nuances in the way it was conceptualised. Different versions of normalisation could equate to different outcomes: *re-integrating* to 'normal' society without recovery, a *return* to 'normality' through recovery, or the construction of an *alternative* 'normality'. This builds on Taylor's observation (2000) that a mothers in a perinatal mental health peer support group want both lateral social comparison which 'normalises' their current difficult emotions, and upward social comparison which holds out hope a return to mainstream 'normality' where they no longer have those difficult emotions.

For some Parents in Mind mothers, discovering that others had similar feelings enabled them to expand their understanding of the range of 'normal' reactions to motherhood, redefining this more widely so that unhappy and anxious feelings were included. This enabled them to overcome shame, disclose their feelings to family and friends, and participate in 'normal' new parent groups, reintegrating into society even if they still had perinatal mental health difficulties. For a second group of mothers (those with milder difficulties), peer support improved their self-concept and coping so that they were restored to 'normality' because they felt better and no longer needed support.

For a third group, peer support was about 'finding your tribe' in a more permanent sense, and this could lead to the creation of a negative 'alternative normality'. These volunteers and mothers

created a narrative in which most mothers were assumed to be struggling, but only the peer support group was honest enough to admit that early motherhood was "*this shit time*", while others were assumed to (probably) put on a false front of coping. This narrative enabled mothers to withstand their alienation from the positive presentation of motherhood they had encountered online and in real life, but did not enable them to move on from negative perceptions of themselves and their babies. Providing the opportunity to vent feelings and giving emotional support brings short term relief, but does not help a person move past their distress (Nils & Rimé, 2012; Rimé, 2009). It may have strengthened group bonds, as feelings of emotional closeness are enhanced by reciprocal disclosure and co-ruminating on negative emotions (Altman & Taylor, 1973; DiGiovanni et al., 2021), but co-ruminating is also associated with increased depression and anxiety (DiGiovanni et al., 2021). If volunteers did not encourage mothers to notice the positives in their lives, there was a risk that a peer support group could actually increase negative feelings.

This could be a subtle judgement call. People in distress tend to want emotional support that validates and does not challenge their negative emotions, particularly if they have low-self-esteem (Marigold et al., 2014; Rimé, 2009). Social support may increase stress if the aspect of support given does not match the aspect desired or needed by the person (Cohen & Wills, 1985; Sarason et al., 1990; Thoits, 1986). There was evidence that more experienced Parents in Mind volunteers personalised the support by assessing whether a mother's immediate need was to have her negative feelings validated, or whether she might also be ready to have her beliefs gently challenged. These can be seen as sequential steps: supportive communication in general is likely to require emotional support before the sharing of information or problem-solving (Feng, 2009).

Creation of a negative 'alternative normality' could lead to a loss of peer identification if one mother appeared to be 'recovering' more than others. It also created a tension between the desire to normalise unhappiness and the desire to present an authentic self, with some volunteers and mothers indicating that the requirements of normalisation might temporarily over-ride those of honesty as they supressed more positive emotions and experiences. In this respect, a peer support group could become a mirror-image of the 'normal' mother's groups in which mothers with perinatal mental health difficulties feel a need to pretend things are better than they really are (Jones et al., 2014a). Ironically, self-silencing about positive experiences in order to fit in with competitive *negativity* about motherhood has also been reported in some 'normal' postnatal groups (McLeish et al., 2021).

Some mothers talked about the oppressive nature of the depictions of happy motherhood they had encountered in social media, but none mentioned the so-called 'slummy mummy' online confessional blogs. Orton-Johnson (2017) analysed these as a sub-genre of subversive resistance to

narratives of the contented natural mother or the groomed 'yummy mummy' (Littler, 2013). She described how bloggers used self-deprecating humour to portray motherhood as frustrating and their own parenting as flawed; and how some readers felt validated by what they perceived as a more honest account of family life. Some blog posts had, nonetheless, attracted judgemental responses from readers. This indicates that these mothers, who were engaged in an online space that was dedicated to relishing a transgressive version of motherhood, still had normative moral lines that they were not comfortable to see crossed. By contrast, Parents in Mind peer supporters were trained to respond non-judgmentally to a mother's disclosure of any thoughts and feelings, and were able to create a truly 'safe space' where some mothers felt able to express themselves authentically for the first time. However, this feeling of safety was <u>not</u> automatically generated for all mothers (specifically if they had low self-esteem and an entrenched negative attribution style) by the simple fact of 'peerness'. It developed as trust was built, which could be through reciprocal self-disclosure and witnessing the active expression of non-judgmental acceptance.

#### 11.5 Who is a peer in perinatal mental health?

The criteria for who could participate in Parents in Mind evolved during the pilot. The initial expectation was that volunteers would have personal experience of perinatal mental health difficulties from which they had recovered, and mothers accessing support would have mild-to-moderate mental health difficulties directly related to having a baby. Later, some volunteers were included who had less specific lived experience or had not fully recovered, and mothers were included whose mental health difficulties were more serious and/or were a continuation of pre-existing difficulties.

These more inclusive criteria meant that support might occur between women who had very different mental health experiences, raising the question of who was a relevant 'peer' for meaningful social comparison. For some mothers, close similarity in mental health experiences was important to normalise their individual thoughts and feelings, generate hope, and establish a 'peer' feeling; but for others, this could be demoralising. Likewise for some mothers, similarity in social or cultural circumstances was also important to establish an appropriate reference group and social bonds; while for others, cultural difference was essential to believe in confidentiality, and social dissimilarity could be reassuring. Some volunteers felt that personal experience of perinatal mental health difficulties intrinsically created 'peerness', while others felt that mental health difficulties were too wide ranging for an individual peer supporter to be able to understand or empathise with all of them. Mixing pregnant and postnatal mothers in a group could also cause some postnatal mothers to feel inhibited about sharing their true experiences.

These complex findings echo the diverse perspectives found in the literatures on mental health peer support and perinatal peer support more generally. The fundamental premise of mental health peer support is that lived experience of mental health difficulties provides unique connection and insight through "the shared experience of emotional and psychological pain" (Mead et al., 2001, p. 6). As noted in section 1.2.5.3, some people with minoritised identities may prefer peer support based on that identity (Billsborough et al., 2017; Faulkner et al., 2013), but it is important to avoid generalisations - some mothers explicitly say they do <u>not</u> want support from a volunteer with the same ethnicity (McLeish & Redshaw, 2015). Helgeson and Gottlieb (2000) suggested that the effectiveness of support groups can be maximised by trying to achieve reasonable homogeneity, but some mothers see attitudes as more important than lived experience: Letourneau et al. (2015) reported that many women with postnatal depression wanted one-to-one support from a non-judgmental person, and considered it ideal *but not essential* that this person had experienced postnatal depression.

The findings from Parents in Mind suggest that perinatal mental health peer experience is one potential source of a non-judgemental, empathetic attitude, but it is neither a guarantee of this attitude nor the only possible source. Local project managers reported that peer experience did not necessarily make volunteers non-judgemental towards all aspects of others mothers' lives, and could make it harder for them to give non-directive information. Volunteers with more limited lived experience of mental health difficulties were just as likely to be empathetic and non-judgemental if they were by nature open and inclusive. However, some mothers' *beliefs* that peers would automatically be understanding, non-judgemental and empathetic, were identified as important motivators of take-up, and perinatal mental health peer experience was essential for prominent programme theories related to social comparison and the mental health aspects of experiential knowledge.

### **11.6 Format of support**

### 11.6.1 **One-to-one and group**

A distinctive feature of Parents in Mind was that it offered both one-to-one and group support. This was an advantage because there were some mothers who felt that self-disclosure would only be safe to one other person (Solano & Dunnam, 1985), while others believed that a one-to-one conversation would be intimidating and pressurise them to speak. There were also mothers who were explicitly looking for friendship and so wanted to attend a group. The pattern was different across the three sites, with the generally more advantaged mothers at site 1 making most use of group support, the

more disadvantaged mothers at site 2 preferring one-to-one support, and neither format gaining traction at site 3.

Many of the positive programme theories for mothers were evidenced in both group and one-to-one settings, although only a peer support group offered mothers the opportunity for downward social comparison, helper-therapy, and increased social support through making new friends. By contrast, almost all of the negative programme theories were *only* identified for horizontal support between mothers in groups.

Different volunteers also had different preferences for group or one-to-one support. Some volunteers were nervous of managing group dynamics, while others enjoyed learning and gaining peer support from each other as they co-facilitated groups. One-to-one support potentially enabled a relationship to develop, and a peer supporter could feel a stronger sense of personally 'making a difference' if things went well. However, there was also the risk that it could feel like a personal failure if the peer supporter was not able to meet the mother's needs safely, or a personal rejection if the mother dropped out of support. These scenarios had to be carefully managed by local project managers, as also reported by Spiby et al. (2015). There was much less emphasis in Parents in Mind on the establishment of strong relationships in one-to-one support, compared to other volunteer programmes where this is often emphasised as the most important aspect of the support (McLeish et al., 2016a). The relationship of trust was considered important, but not necessarily emotional connection. This was influenced by concerns about dependency at site 2, where the majority of oneto-one support was given, and where there was an active policy to prevent long term support between the same volunteer and mother. By contrast, the local project manager at site 3 believed that relationships were the key to effective peer support, but one-to-one relationships had not flourished there.

## 11.6.2 Face-to-face and telephone

Parents in Mind only offered face-to-face support outside the home. Some mothers had difficulties leaving their home, and others were deterred by the cost or non-availability of public transport or the challenge of travelling with several children. Local project managers addressed these barriers in some cases by visiting or telephoning mothers themselves. Only near the end of the pilot were volunteers allowed to use telephones.

This was in contrast to interventions reported in the realist review, six of which were based on oneto-one telephone support from trained peer volunteers in Canada, Singapore and the UK. The review found that the convenience and anonymity of telephone support could encourage take-up, particularly if there were barriers to physical access, if there was already a culture of accessing health

services by telephone, or if it was not culturally acceptable to seek support for perinatal mental health. The finding that the possibility of anonymity may be an attractive feature of peer support by telephone is consistent with research into telephone peer support in other sensitive contexts (Evans et al., 2020). By contrast, the review also found that some mothers saw telephone support as intrusive or impersonal and not conducive to building trusting relationships. In the UK, where there was (at that time) no culture of telehealth, there was comparatively low take-up of telephone peer support when offered, and high drop-out (Sembi, 2018). It is likely that, as in other perinatal volunteer programmes (McLeish & Redshaw, 2015), offering a mixture of face-to-face and telephone support would have the greatest potential to meet mothers' diverse needs.

#### 11.6.3 Length and structure of support

Despite the efforts during the pilot to introduce the concept of a 'set' of peer support sessions at sites 1 and 2, mothers made use of the peer support for extremely varied lengths of time and degrees of intensity, from a single session to over a year of regularly attending a drop-in group. It was not always possible for local project managers to make contact when mothers left the programme, so it was not known whether they were stopping peer support because they felt better, they did not like it, or for an unrelated reason. This made it impossible to determine whether there was a specific amount of peer support that was necessary to activate programme mechanisms, or whether this might be as individual as the mothers themselves, as also found by Billsborough et al. (2017).

#### **11.7 Volunteer recruitment, training, support, retention**

This evaluation demonstrated that volunteers could be effective as one-to-one perinatal mental health peer supporters and also as facilitators for peer support groups, where their skills could prevent or mitigate activation of some of the negative programme theories, as predicted by Helgeson and Gottlieb (2000). Considerable effort was invested in a recruitment process and subsequent support to ensure that volunteers with lived experience of perinatal mental health difficulties were well enough to volunteer. Careful selection, realistic training and ongoing skilled support from a project co-ordinator have consistently been identified as essential to help volunteers or perinatal peer supporters manage the challenges of their roles (McLeish et al., 2016a; McLeish & Redshaw, 2017a; Spiby et al., 2015; Wood, 2020). Parents in Mind added an assessment by a mental health professional before or during training, and access to this clinical support during volunteering. Different volunteers placed different emphasis on the individual or group support they received from the local project manager, on peer support from fellow volunteers, and on the knowledge that formal psychological support from the clinical supporter was available should they need it.

Volunteers with higher current mental health needs and more complex life challenges were most closely 'peers' for mothers who were currently unwell, and they gained the most from training and volunteering in terms of their own confidence and wellbeing. However, these volunteers needed intensive support from the local project managers to cope with their volunteering role and, in some cases, their relationships with each other. They were less able to keep their volunteering commitments, leading to one of the unforeseen aspects of the local project manager's role providing cover as a peer supporter. This dynamic mirrors one of the conclusions of Trickey et al. (2018) - that where the intervention population has complex social needs, attempting to recruit and retain peers with similar characteristics will be challenging, and it may undermine the intervention's viability if the peers experience it as burdensome and do not volunteer as expected (Meglio et al., 2009). Volunteers with more stable lives tended to stay with Parents in Mind longer, and to be more dependable and flexible as peer supporters. Similarly volunteers who had left school without qualifications, or had previously left the labour market, gained the most in terms of confidence and renewed employment prospects, but volunteers who had existing skills were judged by local project managers as being most successful at group facilitation. The emphasis in recruitment shifted to careful assessment of all potential volunteers' aptitude, motivation and values, and the programme was strengthened by including volunteers with a range of personalities, backgrounds and previous experiences.

The Parents in Mind training (24 hours over 8 weeks in the final version) was much longer than in most of the interventions reported in the realist review (0.5-2 days), and contrasts with the experience of some perinatal peer support workers employed in the NHS who may receive no training at all (Wood, 2020). Most volunteers enjoyed the training and found it had increased their knowledge, although they did not necessarily feel ready for their role. In the initial version of the training, the theory of NCT breastfeeding peer support (that the peer supporter should not talk about her own experience at all, in case that is misconstrued as advice) was imported inappropriately into a mental health context. This risked fundamentally undermining the mental health peer supporter role and caused confusion and stress for volunteers, although some ignored the instruction. Clarification of this issue, and the substantial revision of the training to make it more relevant to Parents in Mind, created a strong basis for a shared understanding of what peer supporters were expected to do.

Role confusion has also been reported for NHS peer support workers if there is no guidance (Wood, 2020), and in one-to-one peer support interventions for antenatal and postnatal depression where the peer supporters designed their own support based on what they personally thought would be helpful (Carter et al., 2019; Cust, 2016). There may be a necessary compromise between autonomy

and flexibility if peer support is to be high quality and safe for everyone involved, and likewise between the important principle of co-creation and existing evidence about what it is that works in peer support, for whom, in what circumstances and why. Mental health charity MIND has called for standardised accredited perinatal peer support training to be universally available, and based on the training already developed in different organisations including Parents in Mind (Wood, 2020).

It is common for volunteer programmes to take approximately two years to become established in a local area, and in particular to gain the trust of local health professionals (who are likely to be the key referrers) by building up a track record of safe and effective support (McLeish et al., 2016a). The natural consequence of this is that referrals start slowly, yet a cohort of volunteers must be trained before any referrals are invited and thus there is often an initial phase where there are trained volunteers ready to give support but not enough mothers seeking support (Carter et al., 2019; McLeish et al., 2016b; Sembi, 2018). Parents in Mind staff found effective ways of maintaining morale during this phase. This was reflected in the high retention rate of those peer supporters who completed training and started volunteering, with two-thirds still active after one year and nearly half after two years. This compares favourably to the only intervention in the realist review that reported long term retention – the Mums4Mums study of one-to-one telephone support, in which half of the volunteers left after supporting just one mother (Sembi, 2018). As in other volunteerbased programmes, Parents in Mind staff saw regular training of new cohorts of volunteers (at least once a year) as essential to ensure sustainability.

## **11.8 Peer support and professional support**

Peer support does not purport to be an alternative to professional support for those who need it, although it has been recognised that it may be a sufficient intervention for mothers who are below the threshold for accessing psychological therapy (Royal College of Psychiatrists, 2021). There is a clear overlap between the theories identified for group peer support and the social psychological mechanisms active in group psychotherapy (Scope et al., 2012; Yalom & Leszcz, 2005) (see section 4.3.15), and also other group-based interventions for postnatal depression (Morrell et al., 2016).

In the ideal scenario, a programme such as Parents in Mind would form part of a mixed economy of perinatal mental health support. As well as being offered to mothers with non-clinical mental health difficulties who do not receive professional support, peer support might be offered at the same time as professional perinatal mental health services, or as a 'step-up' or 'step-down' service before or after professional support; and there would be sufficient capacity in specialist services to meet the needs of women whose perinatal mental health difficulties were too severe for peer support (Royal

College of Psychiatrists, 2021). The Parents in Mind pilot operated in a non-ideal scenario where, particularly at sites 2 and 3, specialist perinatal teams were underdeveloped, and where there were long waiting lists and opaque systems for accessing professional support. This placed Parents in Mind in a difficult position. Local project managers sometimes felt moral pressure to support mothers who were seriously unwell because there was nowhere else for them to go, or took on an advocacy role to persuade specialist mental health services to support them. Some mothers came to peer support hoping it would give them something similar to the professional support they were unable to access, and were disappointed that this was not the case; this underlines the importance of being able to explain peer support clearly.

These service pressures also affected the volunteers. Most volunteers understood that they were *'not there to fix people'* (although mothers might, in fact, fix themselves with the help of peer support). On the other hand, where mothers could not access the professional support they needed, some volunteers expressed frustration that the boundaries of peer support prevented them from helping these mothers more comprehensively, and wanted their peer support training to equip them with a more professional approach. Dennis (2003b) cautioned that too much training of peer supporters risked turning them into paraprofessionals with assumed loss 'peerness'. The lines in Parents in Mind were sometimes blurred, not through too much training but because some volunteers (unofficially) drew on their pre-existing professional skills, or applied techniques gained through their own experience of psychological therapies. This was not part of the programme design, but was an important and beneficial part of what some mothers experienced.

A community-based peer support programme is most likely to flourish when it is has strong relationships with local health professionals as referrers and an easy referral route (McLeish et al., 2016a). The national and local project managers invested considerable time in building and maintaining relationships with professionals who would be potential referrers, but referrals were still slow to build up. Professionals' professed enthusiasm for peer support did not necessarily translate into referring mothers to it, and some mothers said that they had been referred only as an afterthought or after prolonged attempts to get help. The ability to self-refer was important for widening the invitation, and also enabled access for mothers who did not trust professionals. Being positioned outside the mental health system in a third sector programme may thus increase the accessibility of peer support for some mothers, while also enabling peer supporters to avoid the complications that can arise for peer workers who are part of services, such as having their role misunderstood or undervalued by professional colleagues (Gillard et al., 2014; Moran et al., 2013; Mowbray et al., 1998; Rebeiro Gruhl et al., 2016; Vandewalle et al., 2018; Wood, 2020). At the same time, paid peer support roles are increasing in perinatal mental health services such as Mother and

Baby Units (Wood, 2020), and these roles offered career progression for some of the Parents in Mind volunteers.

#### **11.9 The challenges of measuring recovery outcomes**

Complex social programmes are intrinsically dynamic as they learn from experience, adapt to changing situations and seek to improve delivery (Pawson et al., 2011), and the challenges that this poses for a outcomes-focused evaluation of third sector peer support have been discussed in Chapter 1 (section 1.2.7). How best to measure recovery 'within' mental health difficulties also remains uncertain. Shanks et al. (2013) identified a variety of possible measures but noted that criterion validity, responsiveness and feasibility were under-investigated. As Stuart et al. (2017) have observed, "if recovery is entirely individual ... against what can it be normed?" (p.292). The theoretically-grounded Peer Support Evaluation Inventory (PSEI), developed by Dennis (2003a) for telephone support, is a promising basis for measuring mothers' perceptions of some recovery constructs specifically expected to be affected by peer support, as well as one-to-one social support mechanisms, and relationship quality. The perceived benefits are grouped into three domains based on stress and coping, social integration, and social construction. However, although content validity of the PSEI was carried out by three experts, no other assessment of psychometric properties was reported. The PSEI includes some potential negative aspects of relationships, but is limited by the omission of any perceived negative impacts on the mother. It is also not suitable to capture the complexities of relationships in a peer support group. The detailed programme theories identified for Parents in Mind could be used to specify expected recovery outcomes from a programme offering both group and one-to-one support, but more work is needed to identify or create appropriate measures for all of them.

#### **11.10** Reflections on the realist approach

The critical realist interrogation of contextualised causal understandings proved a valuable approach to investigating perinatal mental health peer support, integrating social and individual contextual factors with multiple mechanisms based on a mother's or volunteer's reasoning and reactions to the experience of peer support. However, the realist approach was pioneered in social programmes that aimed to produce behaviour change in those using the programme (Pawson & Tilley, 1997). Applying C-M-O analysis to a programme whose outcomes were intended to be primarily psychological rather than behavioural meant that there was sometimes a lack of conceptual clarity about whether to describe a psychological consequence of peer support such as 'increased self-confidence' as the 'reasoning and reaction' part of a mechanism or as an outcome, a challenge also noted by Spiby et al.

(2015). C-M-O analysis is not usually used for programme take-up, but this proved a useful way to explore the ways in which social, local and personal contextual factors may affect a mother's decision and ability to use peer support, thus moving the analysis beyond the traditional narrative of 'barriers and facilitators'.

Although there are quality standards for realist review and realist evaluation published by the RAMESES projects (Wong et al., 2013; Wong et al., 2017), there is no equivalent guidance for theorybased evaluation. There is also no consensus about the best way to present multi-dimensional and interacting C-M-O configurations. The applied realist approach continues to evolve and practitioners debate points through a mailing list hosted by the RAMESES projects

(https://www.ramesesproject.org/). The dynamism of the field generates a degree of insecurity while also opening the way for a degree of creativity. Although this research has been carried out as a critical realist theory-based evaluation incorporating a realist review, it was so heavily influenced by the RAMESES standards and debates that it is unlikely that the findings would have been substantially different had it been formally positioned as a realist evaluation. The decision not to change this positioning was based on the slightly wider and more emancipatory focus attributed by theorists to theory-based evaluation.

#### **11.11 Reflections on research relationships**

Research relationships are understood as part of the methods of realist research (Maxwell, 2012), and this required a reflexive approach about the multiple ways in which relationships might affect the research. My relationships with Parents in Mind staff (see section 6.10.7) facilitated frank interviews exploring complexity, but they also carried the risk that loyalty to people who I respected might cloud my analytical judgement, particularly with respect to challenges encountered by the programme and negative context-mechanism-outcome configurations. I held this in mind as part of reflective memoing, and found it helpful in this respect to have a separation between the period of working with programme staff during the pilot (2016-19), and the later stages of doctoral research without further contact with programme staff.

NCT was the co-funder of the research, but no staff member tried to influence the findings and NCT explicitly endorsed the goal of exploring the negative as well as positive mechanisms and outcomes of Parents in Mind, in order to improve the programme's future delivery. The logic-in-use of programme staff and project advisory group members (that is, how they believed the programme would work) partially informed the initial theory of change for Parents in Mind (see sections 6.6 and 7.3), but they no longer had contact with the research by the stages of theoretical analysis and

interpretation, when this initial theory of change was tested against C-M-O configurations developed from the primary data to create the final theory of change.

## **11.12 Strengths and limitations**

A key strength of this research was the constant iteration between theory and empirical data, ensuring that this research built on existing frameworks and middle range theories, but remained data-grounded. Evaluating three sites simultaneously generated valuable insights into local contextual factors.

The mixed methods approach, and the involvement of a large number of interviewees with different roles, enabled exploration of diverse perspectives, a principled search for alternative explanations, and triangulation of findings, strengthening their credibility. The 71 interviews provided a rich and detailed data-set, and repeated interviews with staff enabled the development of the programme to be tracked in real time, including the ways in which it evolved and the reasons for adaptations. Using a blend of realist and non-realist approaches in interviews ensured that lived experience was honoured, and reduced the risk of confirmation bias while enabling exploration of developing ideas on programme theories.

It was a limitation of this research that it was not possible to interview mothers who did not take up peer support, and there were gaps in the demographic data available about them. Although secondhand reports and explanations from staff and volunteers were used to understand their reasoning, some mechanisms may have been missed. It would also have been ideal to observe peer support groups in action, but this was not possible because of the risk that an observer's presence might disrupt the very peer support dynamics that were being observed. In interviews there were, however, detailed descriptions from volunteers and mothers about conversations in both groups and one-to-one support.

Ideally the realist review would have been completed before the data collection in the primary research, so that every C-M-O configuration in the review's final theoretical model could be discussed with interviewees as part of the theory-based evaluation, and interviews could continue until theoretical saturation was reached. This was not possible, due to the short timeline of the Parents in Mind pilot and the time constraints of a part-time PhD. Iteration between the review and primary research strengthened the review, but limited the primary research in this respect. Nonetheless, there were ample data from the interviews to support comprehensive C-M-O coding.

Finally, it was a limitation that there were quantitative follow-up data available for only 57% of mothers, and the amount (frequency and length) of peer support received by each mother was not accurately recorded. Those who left the peer support without completing a follow-up questionnaire may have had different HADS outcomes. As this was not an outcomes evaluation, this does not affect the conclusions that can be drawn, but it does raise a question for future evaluation of whether to assess the impact of peer support by defining a minimum amount to have been experienced before measuring outcomes.

## **11.13** Contribution to knowledge

A fully-evidenced theory of change for the Parents in Mind programme has been developed. This is the first time that critical realist approach has been applied to understand third sector perinatal mental health peer support; the first time that an evaluation of this support has explored the 'dark logic' of negative programme theories alongside the positive ones; and the first time that the reasons why mothers may or may not take up perinatal mental health peer support have been analysed in depth. It develops existing frameworks and theoretical approaches to peer support by linking contexts, mechanisms and outcomes. This research has provided insight into the complexity of how and why perinatal mental health peer support works in a variety of ways to produce a range of positive and negative outcomes for mothers and volunteer peer supporters in different circumstances. It thus provides a basis for understanding how to improve the delivery of future peer support programmes to achieve the greatest benefits for all involved, and how to evaluate peer support programmes based on what they are actually likely to achieve.

## **11.14** Implications for programmes

#### 11.14.1 Programme design

- Before establishing a new programme, the local context should be carefully considered to
  establish need and accessibility. This includes the birth rate, transport links, the organisation
  of maternity services, existing community organisations and perinatal mental health
  services. It should not be assumed that Parents in Mind-style talking/listening peer support is
  the most appropriate offer for all communities, particularly if mothers do not recognise the
  benefits of talking about emotional distress. Programmes should work with local mothers,
  other third sector organisations and community leaders, to identify how peer support can be
  offered most effectively.
- Although limiting a programme to mothers with 'new' postnatal depression may increase homogeneity in a group, this should be balanced against the benefits of peer support to

mothers with other mental health difficulties including anxiety, and mothers with a history of mental health difficulties.

- Offering a choice of group or one-to-one support will encourage more mothers to make use of peer support. A blend of face-to-face and telephone support will increase accessibility of one-to-one support.
- Programmes offering group support need to decide how to balance the benefits of inclusivity (in mental health and background) against the need to ensure that those attending will feel like a relevant reference group for social comparison.
- Programmes need systems to keep everyone involved emotionally safe, including procedures for responding to a mother in a mental health crisis; this has implications for staffing if leadership roles are part-time.
- It is beneficial for the local programme manager to be trained as a peer supporter, to offer cover as required.
- A new peer support programme needs a realistic timeline of funding to allow for set up and building relationships with referrers, and provision for regular (at least annual) training of new cohorts of volunteers.
- It may be challenging to balance informality against structure, and building peer support relationships against the risk of dependency. Programmes should take account of the local context in deciding how much structure is appropriate.
- Peer support can be misunderstood, leading to disappointment. Communications with mothers and professional referrers should clearly explain what it is and how it can help.
- Programmes should choose outcome measures that reflect how the programme may benefit mothers in a range of ways, including subjective recovery and measurable mental health outcomes.

## 11.14.2 Working with professionals

- Professional referrals are an important access route, particularly for mothers with more serious mental health difficulties. Programmes should create simple referral routes for professionals to use, ideally designed into antenatal and postnatal care pathways to reduce reliance on individual relationships.
- Programmes need referral routes out to specialist services. If there is not sufficient local capacity in perinatal mental health services, there may be pressure on a programme to support mothers who are too unwell for peer support.

## 11.14.3 Peer dynamics

- It is important that staff and volunteers understand how peer support scenarios can have risks as well as benefits, in order to manage these risks and achieve maximum benefits.
- Talking about lived experience is central to many aspects of the experience of mental health peer support, but a programme needs to be clear where the boundaries lie, and how volunteers can safely use basic therapeutic techniques.
- Mothers do not automatically trust mental health peers to be non-judgemental, but trust people with whom they have a good relationship. Erratic group attendance undermines feelings of safety, so drop-in groups are of limited benefit in encouraging open conversations about mental health.
- Mothers look to peer support for affirmation, but careful facilitation is needed to ensure that peer support groups do not develop a 'negative normality' about motherhood.

## 11.14.4 Working with volunteers

- Peer support volunteers can be seen as additional beneficiaries of the programme, with the
  opportunity to improve their emotional wellbeing and gain knowledge and skills. A
  programme needs to decide how long a post-training commitment is expected, and balance
  the need to retain sufficient volunteers against supporting volunteers to access education or
  employment opportunities.
- A programme can be strengthened by recruiting volunteers with a range of backgrounds, skills, and lived experiences. Careful consideration should be given to the support required by volunteers with more complex needs and circumstances, and the commitment that can be reasonably expected from them.
- Programmes should learn from existing models when developing training, which should reflect the programme's theory of change, and prepare volunteers for the difficult situations and feelings that can arise through giving peer support.
- Programmes should offer volunteers robust support and supervision, and create opportunities for ongoing mutual support between volunteers.

## **11.15** Implications for future research

In the realist vision, programme evaluation should be cumulative (Pawson & Tilley, 1997), and it is hoped that this research will be useful for other perinatal peer support programmes in planning evaluations. A process evaluation should, ideally, be followed by an outcomes evaluation, once the

programme model has crystallised (Moore et al., 2015). It remains unresolved as to how an outcomes evaluation of flexible and needs-led community-based perinatal mental health peer support can be simultaneously scientifically rigorous, ethically justified, and consistent with peer support principles.

To enable some consistency and comparability across third sector perinatal mental health peer support programmes, it would beneficial for peer support providers and researchers to discuss collectively the questions of which mental health, personal recovery and other outcomes should be measured, and how they should be measured. It also would also be valuable to consider whether there is a minimum amount of peer support that should be experienced before impact is judged, and how this can be achieved in a flexible programme.

Wider questions arising from this evaluation include:

- How can mothers who do not want to attend a peer support *programme* be enabled to benefit from peer support *mechanisms* in other settings?
- Are the peer support mechanisms identified similar for fathers and co-parents?
- Is peer support stronger when it is a freestanding offer (as in Parents in Mind) or offered alongside other perinatal mental health support including psychological therapy and practical help (as in some other third sector organisations)?

## **11.16 Conclusions**

Perinatal mental health peer support helps mothers in multiple distinctive ways, which complement professional support. It is on a continuum with other forms of perinatal volunteer support, but the specifically peer aspect underlies some key programme mechanisms. Mothers from diverse backgrounds (including very socio-economically disadvantaged mothers) make use of and benefit from peer support if it is available in a format which makes them feel safe to attend, but not all communities see the value in peer support.

This research has demonstrated that the Parents in Mind model is safe and capable of enabling positive change for both mothers and volunteers. The theory of change can be used to equip staff and volunteers with a more detailed understanding of the mechanisms of perinatal mental health peer support, the reasons why some mothers take up peer support and others do not, and the role volunteers can play in mitigating potential negative impacts.

Learning from this research can also inform the selection of future sites for peer support programmes, emphasising the importance of understanding local contextual factors including both practical issues and the local communities' attitudes to mental health and peer support. It is

essential to build relationships with local health professionals who are likely to be the primary referrers; to design outreach strategies that have the widest appeal; to maintain robust procedures for selecting, training and supporting volunteers; and to work with local communities to understand what they want from peer support so that the offer is adapted flexibly to their needs. Outcome measures should not assume that everyone will benefit in the same way. In particular, mothers who develop mild-to-moderate depression and anxiety in the perinatal period may experience measurable improvement in their symptoms, whereas mothers with more severe or more long-term mental health problems may experience emotional benefits that are very meaningful to them, even though their underlying problems remain unresolved.

## **11.17** Final thoughts

"It is impossible to complete the celebrated task of understanding what works, for whom, in what circumstances, in what respects, and why. But the journey itself is worthwhile." (Pawson, 2010, p. 199)

*"Parents in Mind helped me get through my pregnancy and feel sane ...I feel so much better. It does feel like a bit of a miracle!"* (Annie)

"That's the beauty of peer support, it's genuine, absolutely genuine connection... It's a bloody great project." (Tanya(V))

# Appendix A Evidence sources for candidate contextual factors in the realist review

the realist review										
Author, date	Type of study	Place of data collection	Mental health issue							
Abrams, 2009	Qualitative	USA	Postnatal depression							
Abrams, 2011	Qualitative	USA	Postnatal depression							
Ali, 2018	Narrative review (14 studies)	-	Postnatal anxiety							
Baines & Wittkowski, 2013	Systematic review (13 studies)	-	Mental health							
Baines et al., 2013	Questionnaire	UK	Postnatal depression							
Bayrampour et al., 2018	Integrative review (20 studies)	-	Perinatal mental health							
Beck, 1993	Qualitative	USA	Postnatal depression							
Beck, 2002	Meta-synthesis (18 studies)	-	Postnatal depression							
Bennett et al., 2007	Qualitative	Canada	Antenatal depression							
Billsborough et al., 2017	Mixed methods	UK	Mental health peer support							
Bilszta, 2019	Qualitative	Australia	Postnatal depression							
Burr & Chapman, 2004	Qualitative	UK	Depression							
Choi et al., 2005	Qualitative	UK	n/a (motherhood)							
Coates et al., 2014	Qualitative	UK	Postnatal distress							
Coates et al., 2015	Qualitative	UK	Postnatal distress							
Currer, 1984	Mixed methods	UK	Mental health							
Edge & MacKian, 2010	Qualitative	UK	Perinatal depression							
Edge & Rogers, 2005	Qualitative	UK	Perinatal distress							
Evans et al., 2017	Qualitative	UK	Pregnancy anxiety							
Faulkner et al., 2013	Qualitative	UK	Mental health peer support							
Frank, 1998	Theoretical paper	Canada	n/a (illness)							
Franks et al., 2017	Qualitative	UK	Antenatal mental health							
Gardner et al., 2014	Qualitative	UK	Postnatal depression							
Goodman., 2009	Questionnaire	USA	Perinatal depression							
Haga et al., 2012	Qualitative	Norway	Postnatal depression							
Hall ,1998	Qualitative	UK	Postnatal depression							
Hays, 1996	Theoretical book	-	n/a (motherhood)							

Author, date	Type of study	Place of data collection	Mental health issue	
Highet et al., 2014	Qualitative	Australia	Perinatal depression & anxiety	
Iles & Pote, 2015	Qualitative	UK	Postnatal PTSD	
Jones et al., 2014	Meta-ethnography (5 studies)	-	Perinatal mental health	
Khan, 2015	Mixed methods	UK	Perinatal mental health	
Kleinman et al., 1978	Theoretical paper	USA	n/a (illness)	
Knudson-Martin & Silverstein, 2009	Meta-synthesis (9 studies)	-	Postnatal depression	
Masood et al., 2015	Qualitative	UK	Postnatal depression	
Mauthner, 1995	Qualitative	UK	Postnatal depression	
Mauthner, 1999	Qualitative	UK	Postnatal depression	
McIntosh, 1993	Qualitative	UK	Postnatal depression	
McLeish et al., 2016	Rapid review (269 documents)	-	n/a (volunteer support in pregnancy & early years)	
McLeish & Redshaw, 2015	Qualitative	UK	n/a (volunteer one-to-one peer support)	
McLeish & Redshaw, 2017	Qualitative	UK	Perinatal distress	
Morrow et al., 2008	Qualitative	Canada	Postnatal depression	
Nicolson, 1991	Qualitative	UK	Postnatal depression	
Oates et al., 2004	Qualitative	Austria, France, Ireland, Italy, Japan, Portugal, Sweden, Switzerland, Uganda, UK, USA	Postnatal depression	
Parvin et al., 2004	Qualitative	UK	Postnatal distress	
Patel et al., 2013	Qualitative	UK	Postnatal depression	
Raymond, 2009	Qualitative	UK	Antenatal depression	
Rennick-Egglestone et al., 2019	Qualitative	UK	Mental health	
Rosenberg, 1984	Theoretical paper	UK	n/a (support groups)	
RCOG, 2017	Questionnaire	UK	Perinatal mental health	
Schmied et al., 2017	Meta-ethnography (12 studies)	-	Postnatal depression	
Scrandis, 2005	Qualitative	USA	Postnatal depression	

Author, date	Type of study	Place of data collection	Mental health issue
Small et al., 1994	Qualitative	Australia	Postnatal depression
Staneva & Wigginton, 2018	Qualitative	Australia	Antenatal anxiety & depression
Stoppard, 2014	Theoretical book	-	Depression
Tammentie et al., 2004	Qualitative	Finland	Postnatal depression
Templeton et al.,2003	Qualitative	UK	Postnatal depression
Ugarizza, 2002	Qualitative	USA	Postnatal depression
Watson, 2019	Systematic review (15 studies)	-	Perinatal mental health
Wittowski et al., 2011	Qualitative	UK	Postnatal depression

# Appendix B Quality assessment of studies for the realist review

Quality assessment criteria from the Mixed Methods Appraisal Tool (MMAT), version 2018 (Hong et al., 2018), were applied to eight qualitative studies (Table 25), seven reporting the results of RCTs (Table 26), five reporting the results of non-randomised quantitative studies (Table 27), three quantitative descriptive studies (Table 28), and two mixed methods studies (Table 29, Table 30). They were not applied to four papers describing process only (Cust & Carter, 2018; Dennis, 2014a; Ludwick, 2017; Maley, 2002). For the purpose of this assessment, studies reporting answers to open text questions on questionnaires, where these data were not analysed but only used illustratively, were classed as quantitative studies (and appear in the table relevant to their quantitative methodology).

Note: Answer options are Yes, No, Can't tell (CT)

## Table 25 Quality assessment of qualitative studies

Authors	Clear research questions or objectives	Collected data address the research question	1.1 Is the qualitative approach appropriate to answer the research question?	1.2 Are the qualitative data collection methods adequate to address the research question?	1.3 Are the findings adequately derived from the data?	1.4 Is the interpretation of results sufficiently substantiated by data?	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	Comments
Anderson (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	No details about groups or population. Limited use of quotation.
Carter et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Thematic analysis weak.
Carter et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Member checking done. Thematic analysis weak. Limited use of quotation.
Duskin (2005)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	In depth, theorised analysis with strong use of quotation. No justification given for low number of interviewees. Researcher was also group leader, but analysis audited by independent person.
Letourneau et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Useful for context.
Ludwick (2017)	Yes	No	No	No	No	No	No	No data collection apart from researcher's notes. No analysis.
Montgomery et al. (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Analysis focused on stories that fit recovery narrative. Quotes not attributed.
Shorey and Ng (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Thematic analysis limited. Useful for context.
Lynch (2019)	Yes	Yes	Yes	Yes	СТ	No	Yes	Purpose is report on social return on investment.

Authors	Clear research questions or objectives	Collected data address the research question	2.1. Is randomisation appropriately performed?	2.2. Are the groups comparable at baseline?	2.3. Are there complete outcome data? (defined as 80%)	2.4. Are outcome assessors blinded to the intervention provided?	2.5 Did the participants adhere to the assigned intervention?	Comments
Chen et al. (2000)	Yes	Yes	Yes	Yes	Yes	СТ	Yes	4/34 (12%) dropped out. Outcome data for 60/64 (94%). Discussion introduces women's views, but source of these is unclear.
Dennis (2003a)	Yes	Yes	Yes	СТ	Yes	Yes	СТ	No drop-out. Outcome data for 43/44 (98%). Analysis controlled for baseline differences. Used intention to treat analysis. Insufficiently powered for secondary outcomes.
Dennis et al. (2009)	Yes	Yes	Yes	Yes (from 2010 paper)	Yes	Yes	СТ	Intervention initiated for 328/349 (94%). Outcome data for 600/701 (85%) at 24 weeks. Analysis controlled for baseline differences.
Field et al. (2013a)	Yes	Yes	СТ	No	Yes	СТ	Yes	4/48 (8%) dropped out across both conditions. Outcome data for 44/48 (92%)
Field et al. (2013b)	Yes	Yes	СТ	Yes	Yes	Yes	Yes	11/92 (12%) dropped out. Outcome data for 78/92 (85%)
Gjerdingen et al. (2013)	Yes	Yes	Yes	No	Yes	No	СТ	2/39 (5%) dropped out. Outcome data for 36/39 (92%). Analysis controlled for baseline differences.
Shorey et al. (2019)	Yes	Yes	Yes	СТ	Yes	Yes	СТ	No drop out. Outcome data for 113/ 138 (82%). Used intention to treat analysis. Analysis controlled for baseline differences.

Table 26 Quality assessment of quantitative studies reporting results of RCTs

Authors	Clear research questions or objectives	Collected data address the research question	3.1. Are the participants representative of the target population?	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	3.3. Are there complete outcome data?	3.4. Are the confounders accounted for in the design and analysis?	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	Comments
Acacia Family Support (2019)	Yes	Yes	СТ	Yes	No	No	СТ	Outcome data for 159/535 (29%) Limited reporting of statistical results.
Eastwood et al (1995)	Yes	Yes	СТ	Yes	No	Νο	No	5/13 (38%) dropped out. Outcome data on 8/13 (62%) Limited reporting of statistical results. Researcher's observations included.
Letourneau et al. (2015)	Yes	Yes	СТ	Yes	No	No	СТ	30/64 (47%) dropped out / lost to follow up. Outcome data for 34/64 (53%).
Prevatt et al. (2018)	Yes	Yes	СТ	Yes	No	Yes	СТ	Outcome data for 25/45 (56%).
Fairbairn and Kitchener (2020)	Yes	Yes	СТ	Yes	No	No	СТ	Outcome data for 53/126 (42%). Very limited reporting of statistical results.

 Table 27 Quality assessment of quantitative studies reporting results of non-randomised studies

Authors	Clear research questions or objectives	Collected data address the research question	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?	Comments
Dennis (2010)	Yes	Yes	Yes	Yes	Yes	СТ	Yes	221/349 (63%) intervention mothers responded.
Dennis (2013)	Yes	Yes	Yes	Yes	Yes	СТ	Yes	121/175 (69%) volunteers who had supported a mother responded.
Pitts (1999)	Yes	Yes	Yes	Yes	Yes	СТ	No analysis done	34/48 (71%) mothers responded. Large sample of open text answers quoted as list.

## Table 28 Quality assessment of quantitative descriptive studies

# Table 29 Mixed methods studies combining RCT and qualitative methods (part 1)

Authors	Clear research questions or objectives	Collected data address the research question	1.1 Is the qualitative approach appropriate to answer the research question?	1.2 Are the qualitative data collection methods adequate to address the research question?	1.3 Are the findings adequately derived from the data?	1.4 Is the interpret- ation of results sufficiently substant- iated by data?	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretat -ion?	2.1. Is randomis- ation appropriat ely performed ?	2.2. Are the groups compar- able at baseline?	2.3. Are there complete outcome data? (defined as 80%)	2.4. Are outcome assessors blinded to the intervent- ion provided?	2.5 Did the particip- ants adhere to the assigned interven- tion?
Cust (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	СТ	Yes	No	СТ
Sembi (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
Table 30 Mixed methods studies combining RCT and qualitative methods (part 2)

Authors	5.1 Is there an adequate rationale for using a mixed methods design to address the research question?	5.2 Are the different components of the study effectively integrated to answer the research question?	5.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4 Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5 Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Comments
Cust (2016)	Yes	No	No	No	Yes	No drop out.
						Outcome data for 15/15 (100%).
						Weak thematic analysis, few quotations, unattributed.
Sembi (2018)	Yes	No	No	No	Yes	12/14 (86%) completed intervention.
						Outcome data for 22/28 (79%) post-intervention, 14/28 (50%) at 6 month follow up.
						2 participants recruited despite falling outside exclusion criteria.
						Underpowered.
						Comprehensive qualitative analysis with quotations.

## Appendix C Baseline wellbeing monitoring questions

#### Tick the box beside the reply that is closest to how you have been feeling in the past week.

1. I feel tense or 'wound up':	
Most of the time	
A lot of the time	
Time to time, occasionally	
Not at all	

#### 2. I still enjoy the things I used to enjoy:

Definitely as much

Not quite so much

Only a little

Not at all

## 3. I get a sort of frightened feeling like something awful is about to happen:

Very definitely and quite badly	
Yes, but not too badly	

A little, but it doesn't worry me

Not at all

#### I can laugh and see the funny side of things: 4.

As much as I always could

Not quite so much now

Definitely not so much now

Not at all

5. Worrying thoughts go through my mind:	
A great deal of the time	
A lot of the time	
From time to time but not too often	
Only occasionally	

#### 6. I feel cheerful:

_					_			
8.	L	feel	as	if	L	am	slowed	down:

Nearly all	of the	time
incurry an	or the	chine

Very often

Sometimes

Not at all

9. I get a sort of frightened feeling like butterflies in the stomach':	
Not at all	
Dccasionally	
Quite often	

Very often

#### 10. I have lost interest in my appearance:

Definitely

I don't take as much care as I should

I may not take quite as much care

I take just as much care as ever

11.I feel restless as if I have to be on the move:	
Very much indeed	
Quite a lot	
Not very much	
Not at all	

#### 12.I look forward with enjoyment to things:

A much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

13. I get sudden feelings of panic:

-	
Not at all	Very often indeed
Not often	Quite often
Sometimes	Not very often
Most of the time	Not at all
7. I can sit at ease and feel relaxed:	14. I can enjoy a good book or radio or TV programme:

Definitely Often Usually Not often Not at all

programme:

Sometimes

Not often

Very seldom

	l

#### Please circle Yes/No

15. Are you taking any medication for your mental health at the moment? YES/NO

15a. If yes: Do you feel it is helping you feel better? YES/NO

15b. If yes to 15a: How is it helping? Please write your answer in the box.

16. Are you having any counselling or therapy like CBT at the moment? YES/NO

16a. If yes: Do you feel it is helping you feel better? YES/NO

16b. If yes to 16a: How is it helping? Please write your answer in the box.

17. What do you hope to get out of attending Parents in Mind? Please write your answer in the box.

18. Are there any specific goals which you'd like to achieve? If yes, please write your answer in the box.

## Appendix D Follow-up wellbeing monitoring questions

#### Tick the box beside the reply that is closest to how you have been feeling in the past week.

1. I feel tense or 'wound up':	
Most of the time	
A lot of the time	
Time to time, occasionally	
Not at all	

#### 2. I still enjoy the things I used to enjoy:

Definitely as much

Not quite so much

Only a little

Not at all

3. I get a sort of frightened feeling like something awful is about to happen:	
Very definitely and quite badly	
Yes, but not too badly	
A little, but it doesn't worry me	
Not at all	

#### 4. I can laugh and see the funny side of things:

As much as I always could

Not quite so much now

Definitely not so much now

Not at all

5. Worrying thoughts go through my mind:	
A great deal of the time	
A lot of the time	
From time to time but not too often	
Only occasionally	

8. I feel as if I am slowed down:
Nearly all of the time
Very often
Sometimes

Not at all

9. I get a sort of frightened feeling like 'butterflies in the stomach':	
Not at all	
Occasionally	
Quite often	
Very often	

#### 10. I have lost interest in my appearance:

Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

11.I feel restless as if I have to be on the move:			
Very much indeed			
Quite a lot			
Not very much			
Not at all			

#### 12.I look forward with enjoyment to things:

A much as I ever did Rather less than I used to Definitely less than I used to Hardly at all

6. I feel cheerful:	 13. I get sudden feelings of panic:	
Not at all	Very often indeed	
Not often	Quite often	
Sometimes	Not very often	
Most of the time	Not at all	
7. I can sit at ease and feel relaxed:	14. I can enjoy a good book or radio or TV	

Definitely	
Usually	
Not often	
Not at all	

## programme:

Often

Sometimes

Not often

Very seldom

#### Please circle Yes/No

15. Are you taking any medication for your mental health at the moment? YES/NO

15a. If yes: Do you feel it is helping you feel better? YES/NO

15b. If yes to 15a: How is it helping? Please write your answer in the box.

16. Are you having any counselling or therapy like CBT at the moment? YES/NO

16a. If yes: Do you feel it is helping you feel better? YES/NO

16b. If yes to 16a: How is it helping? Please write your answer in the box.

# Thinking now about the effect you feel the peer support has had on you, please tell us how much you agree with these statements:

Parents in Mind has helped me to	Not at all	A little bit	Quite a lot	A lot	Not applicable
17 feel there is someone I can talk to who understands me					
18 find ways of coping when I'm feeling down					
19 feel less isolated and alone					
20 feel more hopeful about the future					
21 know where to get help if I need it					
22 access the services I need					
23 generally feel more positive					
24 achieve the goals I set myself before accessing the service					
25 fulfil my hopes of what the service could do for me					

26. How do you feel the service has met your hopes or goals? Please write your answer in the box:

27. If you haven't been attending, attended then stopped, or are planning to stop, what are the reasons for this?



Appendix E Ethical approval

School of Health Sciences Research Office Northampton Square London EC1V 0HB

Tel: +44 (0) 20 7040 5704

www.city.ac.uk

Ref: PhD/16-17/08

23 December 2016

Dear Jenny and Susan

**Re: Parents in MIND** 

Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once

the project has been completed, and may be asked to complete a brief progress report six months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely

Research Governance Officer

## Appendix F Consent forms and example participant information leaflets (mothers' versions)

## CONSENT FORM (QUALITATIVE)

Title	of Study: Parents in Mind Please initial	box
1.	I have had the project explained to me, and I have read the participant information sheet [INSERT DATE/VERSION], which I may keep for my records. I have been given the opportunity to ask questions and have had them answered to my satisfaction.	
2.	I understand this will involve:	
	<ul> <li>being interviewed by the researcher</li> </ul>	
	allowing the interview to be audiotaped	
3.	This information will be held and processed for the following purposes:	
	<ul> <li>research to find out how peer support affects mothers during pregnancy or the year after birth, and how peer support projects work</li> </ul>	
	<ul> <li>a project report, articles in professional journals, a PhD thesis, presentations at meetings or conferences</li> </ul>	
	I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
4.	I understand that the thesis will be made available in the City Research online repository	
5.	I understand that my participation in the research is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
6.	I agree to City, University of London recording and processing this information about me. I understand that this information will be used only for the purposes set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
7.	I agree to the arrangements for data storage, archiving, sharing.	
8.	I agree to take part in the above study.	

Name of Participant	Signature	Date
Name of Researcher	Signature	Date

### CONSENT FORM (QUANTITATIVE)

#### Title of Study: Parents in Mind

#### Please initial box

1.	I have had the project explained to me, and I have read the participant information sheet [INSERT DATE/VERSION] which I may keep for my records. I have been given the opportunity to ask questions and have had them answered to my satisfaction.	
2.	I understand this will involve allowing the research team to have access to the written information or feedback I have given to Parents in Mind.	
3.	This information will be held and processed for the following purposes:	
	<ul> <li>research to find out how peer support affects mothers during pregnancy or the year after birth, and how peer support projects work</li> </ul>	
	<ul> <li>a project report, articles in professional journals, a PhD thesis, presentations at meetings or conferences</li> </ul>	
	I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
3.	I understand that the thesis will be made available in the City Research online repository	
4.	I agree to allow other researchers to use the anonymous data for further analysis subject to approval from the research team.	
5.	I understand that my participation in the research is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
6.	I agree to City, University of London recording and processing this information about me. I understand that this information will be used only for the purposes set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
7.	I agree to the arrangements for data storage, archiving, sharing.	
8.	I agree to take part in the above study.	

Name of Participant

Signature

Date

Name of Researcher

Signature

Date

#### **PARTICIPANT INFORMATION SHEET (QUALITATIVE)**

#### PARENTS IN MIND STUDY

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

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

Parents in Mind is a study to find out what effect peer support has on mothers who are distressed or have a mental health problem during pregnancy or in the year after birth, and how peer support projects work. The study is going on until 30<sup>th</sup> June 2019. The researcher is doing this research as part of a PhD degree.

#### Why have I been invited?

You have been invited to take part because you have taken part in a Parents in Mind peer support group or you have been supported by a Parents in Mind peer support volunteer. We would like to find out what you think about your experience of peer support.

#### Do I have to take part?

No. Taking part is voluntary. You can choose not to participate in part of the study or all of the study. You can withdraw at any stage of the study without being penalised or disadvantaged in any way. This will not affect the peer support you receive from Parents in Mind.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### What will happen if I take part?

You will be invited to take part in one interview lasting about 30-45 minutes.

- The researcher will arrange a time for an interview that is convenient for you
- The researcher will come to meet you at a place that you choose (for example, your home, a café, a children's centre). If you prefer, the interview can be done by telephone.
- The researcher will interview you about your experience of peer support. With your permission, the interview will be audio-recorded.
- The audio-recording will be typed out but any identifying information will be removed. For example, your name will not be used.
- We will look at what you say alongside what other women have said about their experiences, to understand how peer support affects mothers who are distressed or have a mental health problem during pregnancy or in the year after birth.

#### What do I have to do?

On the day of the interview, the researcher will ask you to sign a form confirming that you consent to taking part in the study. She will then ask you questions about your experience of peer support. You can answer the questions in whatever way you like.

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

You might find it upsetting to talk about your experiences. During the interview you can decide not to answer a question if you don't want to answer it. You can stop the interview at any time.

If you feel upset talking about your experiences, the researcher will give you the number of someone you can call locally for support.

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

You may enjoy talking about your experiences. You will be able to help us find out how peer support affects mothers who are distressed or have a mental health problem and this will help in the future when people want to set up peer support projects.

#### What will happen when the research study stops?

After the research study stops the results will be analysed and reported in various ways, including in a project report, the researcher's PhD thesis, journal articles and presentations.

Your answers will be kept securely on password protected computers and in locked filing cabinets. Data will be kept for 10 years and then destroyed securely (hard copies will be shredded and computer files will be deleted).

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

Your taking part will be completely confidential. Your name will never be used and we will not use any personal information that could identify you.

- We will use an identification code instead of your name. The research team will have access to your answers but will use an identification code instead of your name so that it is anonymous. Other researchers may apply to use the anonymous data for further analysis but this is subject to approval from the research team.
- We will not tell Parents in Mind what you have said to us, unless you tell us something that indicates you or someone else is at risk of harm, or that you are at risk of a mental health crisis. If that happens, we would tell the staff at Parents in Mind so they can make sure you get any help you need.

#### What will happen to results of the research study?

We plan to publish the results in a project report for Parents in Mind, in academic journals, and in a PhD thesis. The thesis will be made available on the City Research Online. We might also present the results at meetings or conferences. It will all be anonymous and if we quote directly from what you have said we will not use your name or any personal details that could identify you. If you would like to receive a summary of the research results, please give us your email address.

#### What will happen if I don't want to carry on with the study?

You can change your mind about taking part at any time, and you don't have to give a reason. If you decide you don't want to carry on, nothing will happen to your support from Parents in Mind and you will not be disadvantaged in any other way.

If you have taken part in an interview and you want to withdraw your interview from the study, please contact Professor Susan Ayers within 4 weeks of the interview (her contact details are at the end of this sheet).

#### What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: "Parents in Mind"

You could also write to the Secretary at:

Secretary to Senate Research Ethics Committee

Research Office, E214 City University London, Northampton Square, London, EC1V OHB

Email:

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

#### Who has reviewed the study?

This study has been approved by City University London School of Health Sciences Research Ethics Committee

#### Further information and contact details

Please contact:

Professor Susan Ayers, Lead, Centre for Maternal and Child Health Research, School of Health Sciences, City University London, Northampton Square, London, EC1V OHB

Email:

#### Thank you for taking the time to read this information sheet

#### PARTICIPANT INFORMATION SHEET (QUANTITIVE)

#### PARENTS IN MIND STUDY

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

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

Parents in Mind is a study to find out what effect peer support has on mothers who are distressed or have a mental health problem during pregnancy or in the year after birth, and how peer support projects work. The study is going on until 30<sup>th</sup> June 2019. The researcher is doing this research as part of a PhD degree.

#### Why have I been invited?

You have been invited to take part because you are going to take part in a Parents in Mind peer support group or be supported by a Parents in Mind peer support volunteer. We would like to find out what you think about your experience of peer support.

#### Do I have to take part?

No. Taking part is voluntary. You can choose not to participate in part of the study or all of the study. You can withdraw at any stage of the study without being penalised or disadvantaged in any way. This will not affect the peer support you receive from Parents in Mind.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### What will happen if I take part?

As part of the Parents in Mind peer support service you will be asked to give regular information and feedback about your emotional wellbeing to ensure you get the support that is best for you.

If you decide to take part in the research, your answers to these questions will be shared with the research team. We will look at your answers alongside other women's answers, to understand how peer support affects mothers who are distressed or have a mental health problem during pregnancy or in the year after birth.

#### What do I have to do?

You do not have to do anything extra apart from sign a form confirming that you consent to your answers to these questions being used anonymously as part of this research.

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

There are no disadvantages or risks. Your answers will be used anonymously.

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

You will be able to help us find out how peer support affects mothers who are distressed or have a mental health problem, and this will help in the future when people want to set up peer support projects.

#### What will happen when the research study stops?

After the research study stops the results will be analysed and reported in various ways, including in a project report, the researcher's PhD thesis, journal articles and presentations.

Your answers will be kept securely on password protected computers and in locked filing cabinets. Data will be kept for 10 years and then destroyed securely (hard copies will be shredded and computer files will be deleted).

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

Your taking part will be completely confidential. Your name will never be used in reporting, and we will also not use any personal information that could identify you.

The research team will have access to your answers but will use an identification code when reporting instead of your name so that it is anonymous. Other researchers may apply to use the anonymous data for further analysis but this is subject to approval from the research team.

#### What will happen to results of the research study?

We plan to publish the results in a project report for Parents in Mind, in academic journals, and in a PhD thesis. The thesis will be made available on the City Research Online. We might also present the results at meetings or conferences. It will all be anonymous and we will not use your name or any personal details that could identify you. If you would like to receive a summary of the research results, please give us your email address.

#### What will happen if I don't want to carry on with the study?

You can change your mind about taking part at any time, and you don't have to give a reason. If you decide you don't want to carry on, nothing will happen to your support from Parents in Mind and you will not be disadvantaged in any other way.

You can also chose to withdraw previous consent to your answers being used anonymously as part of this research, at any time up to 8 weeks after you have given those answers.

If you don't want to carry on with the study, please contact <b>sectors</b> , t	the Parents in Mind
National Project Manager. You can email her on	
What if there is a problem?	

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: "Parents in Mind"

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City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

#### Who has reviewed the study?

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#### Further information and contact details

Please contact:

Professor Susan Ayers, Lead, Centre for Maternal and Child Health Research, School of Health Sciences, City University London, Northampton Square, London, EC1V 0HB

Email: Tel:

Thank you for taking the time to read this information sheet.

## **Appendix G Topic guides**

#### PMHD = perinatal mental health difficulties

#### Supported mothers

- Experience of PMHD, including changes over time, disclosure and how she feels now
- Experience of peer support
  - How she heard about the project
  - $\circ$  What she hoped/expected from the project
  - What type of support she received and for how long/how often
  - What it was like starting peer support
  - What it was like having the peer support
  - What it was like ending peer support
  - The significance of peer experiences
  - What she liked best about the peer support
  - What she would like to change/improve
  - If 1:1 support the development of the relationship and what it meant
  - o If group support her experience of the dynamics within/outside the group
- Her own explanation for any change in mood over time
  - $\circ \quad$  her beliefs about the impact of peer support, how and why
  - o other factors that may have contributed to change
  - o her understandings of the potential mechanisms of change
- Any negative effects of peer support
- Programme theories

#### Volunteer peer supporters

- Experience of PMHD and how she feels now
- Experience of volunteering
  - How she heard about the project
  - Motivation
  - Feelings of readiness following training
  - Support/supervision
  - Content of group sessions
  - Perception of group dynamics
  - Establishing 1:1 support relationships
  - Managing endings
- The impact of peer support
  - $\circ$   $\;$  Understanding of the potential mechanisms of change
- The impact of volunteering
  - on her mental health and wellbeing
  - o on her generally (including future plans)
  - o any negative impacts
  - o the hardest thing about being a peer supporter

- the best thing about being a peer supporter
- Programme theories

#### **Project staff (first interview)**

- Background and how she came to work for the project
- Understanding of PMHD
- Barriers and facilitators to setting up and running the project
  - and whether these have changed over time
- Process issues
  - referral process (planned and actual)
  - $\circ$   $\;$  initial interview with mothers and screening for suitability
  - o allocation to group/individual support
  - matching for 1:1 support
  - $\circ$  relationships within the project
  - deciding content of group sessions
  - $\circ \quad \text{safeguarding issues} \\$
  - o managing endings
  - o relationships with external stakeholders
  - $\circ \quad \text{data collection} \quad$
  - o time management
  - o project resources
  - $\circ$  sustainability
- High points, low points
- Key learning so far
- Programme theories

#### Trainers

- Professional background, history with NCT
- What has experience been like as trainer for PIM high points, low points?
- Lived experience
  - Does trainer need it too?
  - How are volunteers encouraged to use it now?
  - How do you teach that?
- Advice vs information
- Group hosting vs facilitation
- Accreditation is it important?
- Ongoing role in reflective support (& why?)
- Programme theories
- Key learning so far
- Anything else that needs to change?

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