Judgement, hope and identity: Stories of health care and mothering in the perinatal period from women receiving opioid treatment

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STATEMENT OF AUTHENTICATION

I, Susan Rosalind Harvey, declare that this thesis is my own work, and the result of my research endeavour. It contains no material previously published or written by another person except where acknowledged in the text. In addition, the thesis does not contain material submitted for the award of another degree at any other institution.

Ethical approval for the study presented in this thesis was obtained from the Human Research Ethics Committees of Sydney West Area Health Service, and the University of Western Sydney. Participants were requested to read a participant information document and informed consent was obtained prior to data collection.

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ABSTRACT

This thesis presents the findings of an in depth narrative study about women who receive treatment for opioid dependence. In particular, it examines the experiences this group of women have of health services during pregnancy and up until the first year of their baby’s life. Women receiving treatment for opioid dependence are known to have complex health and social needs and commonly have a range of co-existing personal and social factors impacting on their health and well-being. Mental health issues, poverty, and exposure to physical and emotional abuse including domestic violence not only affect women, but also the health and development of children in their care. However, women receiving opioid treatment are generally reluctant to engage with health and support services.

The limited utilisation of health and support services by this cohort of women is often underpinned by the women’s fear of judgement. The women expect to be judged as ‘bad mothers’ due to their history of substance misuse, and particularly fear the possible loss of custody of their child, if child protection services become involved in any way. As a result, this group of women are generally cautious and guarded in their interactions with health professionals. It is therefore often difficult for services to respond to research and government policy recommending prevention and early intervention strategies if challenges of engagement are not adequately addressed.

The aim of this study was to examine how women receiving opioid substitution therapy make meaning of their interactions with health and other services in the perinatal period. Increased knowledge of the experiences of women receiving opioid treatment as they become first-time parents, or parents again has provided the opportunity to hear their ‘voice’, understand what acts as barriers or enables service use, and develop services to better meet their needs. Unlike most research in this area, this study endeavours to consider the women’s experience across all stages of the perinatal period.

A qualitative approach and narrative methodology provided the theoretical framework for collecting data in a way that allowed participants the greatest
opportunity to ‘tell their story’. Six women participated in a face to face interview with the researcher on two separate occasions, two to six months apart. The interviews were conducted in a large metropolitan Area Health Service and occurred at the community-based clinic providing opioid treatment for each participant.

Two main themes, judgement and hope, emerged through data analysis and were closely interwoven. The findings of the study are firstly presented in the collective story of ‘Nina’, where common elements of the women’s stories were brought together in chronological order and facets of judgement and hope are juxtaposed. The themes of judgement and hope are then considered separately under the chapter headings of ‘Methadone baby’, and ‘Being a good mother’. Becoming pregnant and the transition to motherhood was a ‘turning point’ in the lives of all the women enrolled in the study. It provided the impetus for rethinking their identity and a future for themselves and their children.

Narratives of all the women in the study included their desire to move away from their identity as a drug user, or ‘junkie’ and become accepted as a ‘good mother’. The women’s perceptions of judgement by health professionals increased feelings of self judgement and guilt. Although the women were receiving treatment, the negative identity of a drug user was difficult to change, and was accentuated by the ‘surveillance’ role and underlying power of health professionals. The women were aware of the mandated responsibility of health professionals to inform child protection services of concerns for their child’s safety, impacting on the development of a relationship built on trust.

The focus of the women in the study was to reconstruct their lives despite adversity, and the dichotomy of surveillance and support from services. The concept of resilience was explored to better understand factors that enabled the women to develop a positive outlook regarding the future with their child. Hope assisted the women to move towards acceptance as a ‘good mother’. Barriers to engagement were minimised if individual health professionals and services were non-judgemental, flexible and supported the women’s mothering. For the women, a better future meant maintaining the custody of their child, becoming a ‘normal’ mother, and being able to feel comfortable enough to ask for help when it was needed.
This study provides a greater understanding of the importance of becoming a mother to women receiving opioid treatment in the perinatal period. It highlights the opportunity for services to respond to the women’s needs in a positive way and to develop a trusting relationship over time. Although the study has focused on the experiences of women, there are also implications for the children in their care.
CHAPTER ONE

INTRODUCTION

Background

Women receiving treatment for opioid dependence commonly experience complex health and social issues and they, and their children, are considered by society to be a group most in need of health and welfare services. Yet, this group of women are generally reluctant to engage with services. Fear of judgement as a ‘bad mother’, and especially the fear of child protection services and the potential loss of custody of their child impacts on how the women perceive individual professionals and services (Banwell & Bammer, 2006; Keys, 2007; Marcellus, 2005). The women are aware of the mandatory reporting role of midwives, nurses and other clinicians involved in their care and many have concerns that acceptance of support might, or will result in a report to child protection services (Marcellus, 2005; Radcliffe, 2011). However, in deciding not to engage in services, the health care and support needs of the women and the children are less likely to be met; increasing the potential risk of short and long term health issues for this group (Australian Institute of Health and Welfare, 2011; Sword et al., 2009).

The aim of the study was to examine how women receiving opioid treatment make meaning of their interactions with health and other services in the perinatal period. At this time, the women are not only clients of a drug and alcohol service, but also clients of a range of other services offered to all women in pregnancy and after the birth of their baby. In particular, the thesis focuses on what can be learnt from the stories of six Australian women as they experience maternity, child health and other services, such as child protection services, in conjunction with treatment for problem substance use.

I am a child and family health nurse, and my interest in undertaking research in this area stems from my commitment to the principles of primary health care;
particular, improving access and equity for families with identified vulnerabilities. In 2006, I had the opportunity to be involved in a review of early childhood and parenting services at opioid treatment clinics in a large Area Health Service of New South Wales. The staff interviewed for the review indicated that providing early childhood support for women receiving opioid treatment included three key components: the development of a trusting relationship, maintaining continuity of care and a multidisciplinary approach, and the importance of staff education, support and professional development. The proof of a journal article reporting the findings of the review, from the perspective of staff, can be found in Appendix 1 (Harvey, Schmied, Nicholls, & Dahlen, in press). This study has been prompted by my interest in the perspective of the women, not only of early childhood support, but of their experience of services throughout the perinatal period.

At the commencement of this study, I was particularly interested in addressing the following issues or questions:

- What facilitates or impedes engagement with maternity and community based services aiming to promote the health of this cohort of women and their children?
- How can services better respond to the specific and complex needs of women receiving opioid treatment in the perinatal period?
- What can be learnt about improving strategies for prevention and early intervention to reduce the intergenerational effect of problem substance use?
- Are there factors that protect women and children or lead to improved outcomes that need to be better understood?

These questions are not new and some questions have been previously researched; however, recommendations from published studies call for additional research to be undertaken in this area (Dawe, Frye, Best, Moss, & Atkinson, 2007; Milligan et al., 2010). Increasing attention on how to best support women receiving opioid treatment in the perinatal period has become more of a focus for researchers and governments over the last 10-15 years. There continues to be a need for in-depth qualitative research to describe and interpret women’s experience, as well as large population-based and mixed method studies to report short and long-term outcomes. It is important that the voice of this group of women is heard and their experiences
are considered in any discussion of ‘best practice’ and/or realignment of services aiming to improve health care.

The qualitative research undertaken for this thesis sought to build on the preliminary work I had undertaken in the review, by documenting in depth the experiences of the women from their perspective, rather than from the perspective of health care providers. All stages of the perinatal period, defined by Barnett (2011) as the time of conception to one year postpartum, were included in the study rather than being limited to the women’s experiences of services during one component of the perinatal period for example, pregnancy or post-partum. First-hand knowledge was gained about what was important to the women across the continuum of care; a distinction from many other studies. The study adds to existing knowledge regarding engagement with services by families known to have a range of vulnerabilities.

Recent quantitative research at a national level indicates the potential extent of the problem and social perceptions. The prevalence of heroin use in Australia is small in comparison to other drug use, however cumulative risk and vulnerability and the long-term effect on children is of concern to health and child protection authorities. The National Drug Strategy Household Drug Survey (Australian Institute of Health and Welfare, 2011) undertaken in 2010 surveyed over 26,000 people in Australia with the following results. The prevalence of heroin use by people over 14 years of age was 0.2% in the previous 12 months, and 1.4% of those surveyed had ever used heroin in their lifetime. This rate has remained stable since 2001 and is in line with reports of prevalence in other countries (World Health Organisation, 2009). The age of initiation of heroin use between 1995 and 2010 was found to be on average, 20-21 years and drug use was at its peak at the age of 20-29 years; child-bearing years for women. Illicit substance use was also associated with higher levels of psychological distress and the diagnosis or treatment of mental illness in comparison to those who did not identify illicit substance use (Australian Institute of Health and Welfare, 2011).

Illicit substance use, including the use of heroin, is a major risk factor for the poor health of women and their children. Maternal illicit substance use can result in infections such as HIV/AIDS and Hepatitis C, premature birth, mental illness, suicide, self-inflicted injury and overdose (Commonwealth of Australia, 2011; Dawe
et al., 2007). In addition, infants have increased risk of low birth-weight, and Neonatal Abstinence Syndrome (NAS) with associated neurological irritability, seizures and feeding difficulties which may require care in a neonatal intensive care unit (NICU) or special care nursery (SCN) (Blandthorn, Foster, & Love, 2011; Commonwealth of Australia, 2006). Infants are also likely to be at higher risk of Sudden Unexpected Deaths in Infancy (SUDI) which is known to be associated with exposure to tobacco smoke, and co-sleeping where parents are sleeping heavily due to any form of sedating substance - including prescription medications, methadone and alcohol (Commonwealth of Australia, 2006 p.16-17).

To examine the risk factors and significant adverse outcomes, earlier research initially concentrated on the physical effect of substance misuse on the fetus and the impact on infant morbidity and mortality. As a result, funding was provided for the establishment of services known as DUPS (Drug Use in Pregnancy Service) or CUPS (Chemical Use in Pregnancy Service) in Australia and in other developed countries. Subsequent research has also focused on the mother and understanding how clusters of adverse psychosocial factors contribute to the environment in which care is provided to the child after birth, and the ensuing impact on the development and long-term health of the child.

The need for detection and intervention in the early years has been demonstrated in a number of ways. Responsive parenting and the capacity to provide for the needs of the child are more difficult when parents have their own health care needs and psychosocial issues. Maternal substance use or treatment is not only linked to mental health issues and disorders, but also to domestic violence, involvement of child protection services, unemployment, poverty, and reduced levels of education (Dawe & Harnett, 2007; Keys, 2007; Parkinson, 2011). These factors exacerbate the major life-transition and known period of adjustment of becoming a parent, especially for the first time. Research on early brain development and the importance of a secure parent-infant attachment (Horowitz, Logsdon, & Anderson, 2005; Stevenson-Hinde, 2007) has laid the foundation for prevention, early detection and early intervention. Governments have responded to research in this area by introducing strategies based on recognition of the importance of the ‘early years’ (Commonwealth of Australia, 2009; NSW Department of Health, 2009); a crucial time for the development of physical and mental health.
Recent research in Australia by the National Drug and Research Centre (Taplin & Mattic, 2011) has examined the association between mothers using illicit substances and involvement of child protection services. The study findings report an increase in the involvement of child protection services by 1:3 if the mother had mental health problems (prescribed psychiatric medication at the time of the study), and by 1:4 for each additional child after the first child. These findings demonstrate that the association with child protection services is influenced by factors other than maternal use of illicit substances alone. Substantiated reports to child protection services of significant risk of harm indicates that children are at risk of child maltreatment where parents engage in substance misuse (Callaghan, Crimmins, & Schweitzer, 2011). In a small number of cases children have been found to be victims of severe neglect, and some have died as a result of neglect and/or violence in the home.

However, the report by Taplin and Mattic (2011) also identified protective factors, such as social support provided by the women’s mothers, could reduce the likelihood of involvement by child protection services.

Judgements, stigma and prejudices associated with women who use illicit substances may affect how health and support services are provided. Opioid dependence is a complex and challenging health issue historically often seen as a “disorder of willpower, reflecting poorly on the character of the individual” (World Health Organisation, 2009 p.6). Questions in the National Drug Strategy Household Drug Survey (Commonwealth of Australia, 2011) related to community attitudes to drug use indicated a disproportionate and high level of concern in relation to heroin. Thirty-one percent of people identified heroin as the drug most associated with drug problems, although tobacco, alcohol and other licit and illicit drugs have a higher prevalence of use. Health care providers, as a subset of the community may have similar attitudes and concerns however this is less well known.

The recommended treatment of opioid dependence now includes both pharmacological and psychological interventions to maximise outcomes. Opioid treatment for women who are pregnant or breastfeeding consists of opioid antagonist maintenance treatment with methadone or buprenorphine. Treatment by opioid withdrawal is considered to be a “high-risk option” (p.51) because of the increased risk of spontaneous abortion or premature labour and a greater possibility of relapse to heroin or other opioid use, impacting on the woman’s ability to care for a
child/children (World Health Organisation, 2009). Opioid treatment is mostly required long-term as a means of reducing the harmful consequences of opioid dependence and to improve quality of life and well-being. Although support from health services and through social networks is known to assist women who use illicit substances, the challenge remains as to how to improve their engagement with services.

**Study Aim and Objectives**

The aim of the study was to examine how women receiving opioid treatment make meaning of their interactions with health and other services in the perinatal period. Specifically, the following study objectives were addressed:

- To analyse the narratives of women relating to their engagement in opioid treatment in the perinatal period
- To identify and explore barriers to accessing health services related to maternity care and child health care
- To identify and explore factors that enable women receiving opioid treatment to access health and other services in the perinatal period
- To discuss how health services for women receiving opioid treatment, and their children can be strengthened with a view to improving outcomes for both.

**Definitions**

- **Perinatal period** – time of conception to one year post-partum (Barnett, 2011)
- **Opioid treatment** – referred to in this study as the pharmacological treatment and psychological support provided for opioid dependence through an opioid treatment program in NSW, Australia. In the literature, opioid treatment may also be referred to as methadone maintenance treatment or opioid substitution therapy.

This study was an in-depth qualitative study that used narrative analysis to inform the approach to data collection, and the analysis of data. Six women were recruited for the study and each woman was already enrolled in an opioid treatment program at one of three different sites in a large Area Health Service in Sydney. They were receiving treatment for previous heroin or street methadone use and had access to psychosocial assessment and support in conjunction with pharmacotherapy.
Outline of Thesis

A brief overview of each chapter and links to relevant appendices is described below.

Chapter 2 – Literature Review

The literature review consists of four sections which consider mothering in general, mothering in the context of receiving opioid treatment, services available to support women in the perinatal period, and the experience of women receiving opioid treatment as they come into contact with universal and targeted services. The role of midwives and child and family health nurses in providing support to women in the perinatal period is reviewed as well as the provision of support by drug and alcohol services. Both negative and positive experiences of services by women receiving opioid treatment, or women with a history of ‘illicit drug use’ or ‘problem substance use’, are discussed. This section includes consideration of the impact of power on the development of trust between service providers and families with complex needs, and the concept of power is explored further in the discussion of the study findings (Chapter 7).

Chapter 3 – Methodology

The methodology and method for the thesis is discussed in detail in this chapter. Narrative Inquiry is described and its relevance as the theoretical framework for the study examined. An explanation of the method used for the study follows, and this includes information regarding the research setting, recruitment of study participants, as well as data collection and management. The final sections of this chapter consider the process and challenges of data analysis, ethical considerations and my personal reflections on critical reflexivity and the role of the researcher in qualitative research. The privacy of the study participants, family members mentioned in their stories, and staff, is maintained by use of pseudonyms throughout the thesis.

Chapter 4 – Findings: ‘Nina’s Story’

‘Nina’s Story’ is the collective story of the six participants who participated in the study. In line with the methodology, it provides a narrative of the journey of one woman, assigned the name ‘Nina’, from early pregnancy to approximately 6 months after her baby’s birth. The intention of ‘Nina’s story is to provide a chronological
and more complete story of the women’s experiences which are later ‘unravelled’ for presentation in the subsequent findings chapters. Although there are many similarities in the stories of the participants, each woman is unique and it is important that her individual story is also heard. For this reason, the story of each participant can be found in the Appendices. Some stories are longer than others in line with the length of the interviews and the depth of their story, and are related in their ‘own voice’.

Chapter 5 – Findings: ‘Methadone Baby’

Chapter 5 begins the more detailed presentation of findings from the analysis of the data. ‘Methadone Baby’ brings together elements from the women’s stories associated with the major theme of judgement. Judgement by others or fear of judgement by others was a central component of all the women’s stories of their experience of services. Self-judgement was also an important part of each story, and to a lesser extent, judgement by family members or the community. The term, ‘methadone baby’ encapsulates these different levels of judgement felt by the women. Their worthiness to be a mother is particularly brought into question by others and themselves if their baby required treatment after birth to manage Neonatal Abstinence Syndrome (NAS).

Chapter 6 – Findings: ‘Being a Good Mother’

Chapter 6 mirrors the presentation of data analysis found in Chapter 5, however the focus is on the positive rather than more negative experiences of the women in the study. ‘Being a Good Mother’ describes the major theme of hope that emerged alongside judgment in analysis of the data. Each of the women’s stories incorporated their hope of being a ‘good mother’ and wanting to care well for their baby. Pregnancy was identified as the catalyst for change as the women in the study considered their lives and then took on the responsibility of motherhood. The women sought to substantiate and legitimise their role as a good mother and their stories provided examples of how they cared for their baby, including attempts to breastfeed.
Chapter 7 – Discussion

This chapter considers the significance of the findings in light of other knowledge. Four key areas are discussed under the following sub-headings: identity, surveillance, resilience, and hope for a better future. The discussion chapter provides a deeper understanding of factors that act as barriers or facilitate the use of health services by women receiving opioid treatment in the perinatal period. In keeping with the themes identified in analysis of the data, the first two sections of the discussion chapter predominately relate to the theme of judgement (identity and surveillance) and the two final sections relate to the theme of hope (resilience and a better future).

The focus of the section on ‘identity’ reflects the participants desire to shift from the identity of a drug-user, to the more positive and acceptable identity of a ‘good mother’. The work of Goffman (1963) and other authors on identity and stigma is explored, followed by consideration of the concept of surveillance and the power inherent in the roles of health and welfare workers (Foucault, 1973; Peterson & Bunton, 1997). Factors contributing to the way the women were able to deal with personal difficulties, move towards their goal of being ‘good mothers’, and maintain custody of their children, is discussed in the third section under the sub-heading of ‘resilience’. The final section of the discussion, ‘Hope for a better future’ links resilience and a new identity to improved outcomes for the women and their children. A better future for services seeking to provide a holistic approach to care, including support to break the vicious cycle of intergenerational issues, is also considered in this section.

Chapter 8 - Conclusion

The final chapter of the thesis reviews the rationale for the study and considers the value of utilising a narrative methodology for research regarding women receiving opioid treatment. The limitations of the study are then discussed, followed by a section on implications for services. The chapter provides recommendations for future research and closes with some final critical reflexivity in the form of a progressive picture of the methodology and a personal reflection.

This brings the introductory chapter (Chapter 1) to a close. A review of literature relevant to the study is found in the following chapter.
CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter provides a background to the study by examining the relevant literature. As outlined in the introduction (Chapter 1), the literature review is presented in four sections. Firstly, it begins by broadly examining some of the key issues, or concerns, for women as mothers. Secondly, literature regarding the particular mothering experience of women who are receiving opioid treatment is considered. The third section of the literature review focuses on the way health services provide support for women during the perinatal period, and includes information regarding current government initiatives. The role of maternity and community health services in providing care, alongside treatment and support from drug and alcohol services, is also reviewed. The final section of the chapter concentrates on what is known about how women receiving opioid treatment experience these universal and targeted services in the perinatal period. Although the focus of this study is on women’s experiences of seeking maternity and early childhood health and other services, a beginning look at the literature in this field indicates the importance of understanding how perceptions, and particularly how social constructions of mothering and motherhood in contemporary Australian society, influence the experience of women who are mothers and who are also on opioid treatment programs.

Journal articles were accessed by searching the CINAHL Plus and Scopus electronic data bases, and their reference lists provided a useful means of identifying important books and government publications for inclusion in the review. The review focuses on nursing and midwifery literature from Australia and overseas, as well as literature from the drug and alcohol field. The complexity of the issues associated with problem substance use also required a review of literature from the areas of child
protection and the social sciences. Combinations of the following key words were used in the search process: opioid, methadone maintenance, substance abuse, problem substance use, illicit substance use; integrated models of care, child and family health, nursing, midwifery, drug and alcohol, mothers, parenting, and vulnerable families. Each search was limited to the publication date within 2000-2011.

The literature predominately includes both qualitative and quantitative studies that are reported as original research as well as a range of systematic reviews from Australia, Canada, New Zealand, Scandinavia, and the United Kingdom. ‘Google’ was also used as a search engine to access international, national and state government reports, policies and guidelines.

### 2.2 Women as mothers

There are several key issues or concerns for women in the mothering role, which are underpinned by a culturally acceptable gender role. There is an expectation by many in society that women will become mothers, and the reproductive function of women has become central to many discourses regarding identity and motherhood (Craig & O'Dell, 2011; Doane & Hodges, 1993). Divergent meanings have been attributed to motherhood, ranging from fulfilment to subjugation. For some women, becoming a mother can be complicated by “trying to make sense of their own memories of being mothered”, if the protection and nurturing expected of mothers was not experienced (Fowler & Lee, 2004 p.39).

The feminist writings of Rich (1993) acknowledge that motherhood can be the starting point for personal growth and happiness; however, reproduction has generally been viewed by feminists as a source of oppression of women, particularly until a level of freedom was available through safe and effective contraception (Granzow, 2007). In contemporary Western culture, motherhood has been portrayed as “part of a powerful nuclear family ideology that permeates all of society, and is defined and delineated by strong social norms” (May, 2008 p.471). This idealisation of motherhood sometimes now includes the ‘yummy mummy’ who is middle class, attractive, healthy, sexy and heterosexual (Craig & O’Dell 2011); further marginalising those women whose experience of motherhood differs from the
‘norm’. In contrast, the term ‘broken family’ is commonly used to depict families cared for by a lone mother (May 2008) or ‘single parent’. Other women who often face prejudice as mothers include those who are adolescent (Keys, 2007), lesbian (Fairtlough, 2008), or have a disability (Nario-Redmond, 2010).

Beliefs regarding women as mothers set the context for value judgments of individual and collective groups of women regarding their suitability for motherhood. Carpenter and Austin (2007) refer to common and accepted beliefs found in the phrases, “women are biologically destined to be care-givers and nurturers”, “the mother is the ultimate teacher” and “the measure of the mother is her child” (p.660). Although caring for a child involves both parents, women traditionally take responsibility for care-giving and are also held more accountable than men for the child. Jackson and Mannix (2004), use the term ‘mother blaming’ to portray the way society holds women to account for the “actions, behaviour, health and wellbeing” of their child for life, the environment in which the child grows and develops, as well as responsibility for “their own predicaments, such as being abandoned or living in poverty” (p.151).

The ideal of the ‘good mother’ is commonly accepted as a mother who altruistically “devotes unlimited amounts of love, time, patience and physical labour to the well-being of their [her] children” (Banwell & Bammer, 2006 p.506). This ideal now incorporates the concept of the “SuperMom”; an unrealistic expectation that a mother will be able to meet all needs of her children, as well of the demands of a successful professional and personal life (Ratnapalan & Batty, 2009). Most mothers inherently want to provide the best care of their child. However, the expectations of others can be challenging and detrimental to mothering confidence. Winnicott (1960), a paediatrician and psychoanalyst prominent in the 1950s to 1960s, explored the early relationship between a mother and her child, and introduced the concept of the ‘good-enough’ mother. In this concept, the foundations for health and the child’s development were seen to be provided by an ordinary level of loving care and protection from the mother, rather than an expectation of perfection in mothering. Although Winnicott’s concept of the ‘good enough’ mother reduces expectations of mothering for women and health professionals, it is open to criticism that ‘good enough’ mothering is also an idealistic yardstick by which a number of mothers could be found wanting.
Becoming a mother, especially for the first time, has been recognised as a major life event due to the complexity of a changed identity, lifestyle and impact on personal relationships (Dahlen, Barclay, & Homer, 2010). There is a general consensus that a time of adjustment or transition is required for women to become more at ease with their new identity, and manage its changing physical and emotional demands (Dahlen, Barclay, & Homer, 2008; Dahlen et al., 2010; Newman, Fowler, & Cashin, 2011). Motherhood can bring great joy and feelings of fulfilment. Women also commonly report feeling overwhelmed, isolated and exhausted by the motherhood role, where the reality can be very different to their expectations (Dowdell, Fenwick, Bartu, & Sharp, 2007; Emmanuel & St. John, 2010). Part of this process is an adjustment to the loss of their former identity while embracing the development of a relationship with their new baby, and renegotiating other personal relationships (Dahlen et al. 2010). The transition involved in new motherhood may be mediated by factors such as the woman’s previous experience of infants, the social support available from family and friends, and the infant’s behaviour and needs (Barclay, Everitt, Rogan, Schmied, & Wyllie, 1997; Emmanuel & St. John, 2010).

The judgements of others can reinforce the mother’s own feelings of inadequacy as a mother. A study of first time mothers found that a negative self-perception, or opinions of others can challenge the goal of fulfilling the motherhood role (Immelman, 2009). Part of the difficulty is for women to somehow know and follow the ‘rules’, which over the years have developed from an inner confidence of trusting in more instinctive abilities, ‘mother knows best’ (Craig & O'Dell, 2011; Wilson, 2003); to a more structured and scientific approach to being a mother. A proportion of women need additional support, including counselling and treatment in the perinatal period. Women who already have a level of anxiety and depression are known to be more at risk of depression in the baby’s first year of life (Grant, McMahon, & Austin, 2008). Around 1 in 7 women are affected by postnatal depression (beyondblue, 2011; Buist et al., 2008), resulting in additional difficulties in adjusting to motherhood. Depression, anxiety and other mental health disorders are known to affect the development of a secure parent-infant attachment, as well as long term mental health outcomes for the infant (beyondblue, 2011; Buist et al., 2006; Grant et al., 2008; Hardy, 2007). Furthermore, there are increasing studies
reporting a strong association between intimate partner violence and postnatal depression (Woolhouse, Gartland, Hegarty, Donath, & Brown, 2012).

In Western society, the normal processes of birth, breastfeeding and parenting have been influenced by a medical and psychological approach aiming to reduce risk for the mother and infant. These admirable goals can, however, identify women who “fail to adjust to motherhood or are unsuccessful in bonding with their baby from a scientific observer’s point of view” (Rogan, Schmied, Barclay, Everitt, & Wyllie, 1997 p.877). Identification of such ‘deficits’ may not take the context of motherhood into consideration or seek to understand the perspective of the women. A greater awareness of the importance of identifying protective factors in a family assessment is now reflected in health policy (NSW Department of Health, 2009b). In comparison, the individual approach of health professionals continues to have a powerful influence on women’s feelings of judgement as an inadequate mother (Jack, DiCenso, & Lohfeld, 2005; Normandale, 2001; Radcliffe, 2011).

Pregnancy and birth offer the first opportunities for women to demonstrate their capacity to be regarded as ‘good’ mothers, as choices are made regarding antenatal care and birthing. In reality, the goal of a normal birth may instead result in medical and/or surgical intervention, and even become a traumatic experience requiring forgiveness and redemption (Thomson & Downe, 2010).

Another ‘standard’ for demonstrating success in early motherhood is the ability to breastfeed (Burns, Schmied, Sheehan, & Fenwick, 2010; Ryan, Bissell, & Alexander, 2010; Schmied & Lupton, 2001). Ryan et al (2010) suggest that a woman’s sense of self is affected by “the embodied nature of breastfeeding and the intensity of the relationship between a mother and her baby” (p.952). They considered the ‘moral work’ undertaken by women to present themselves as a ‘breastfeeding mother’ and how women maintain this view despite feeding difficulties, for example by providing their baby with expressed breast milk. Difficulties with breastfeeding and the choice to ‘give up’ do not easily fit with our society’s view of a ‘good’ mother. These difficulties commonly result in feelings of guilt from women who are unable to meet this goal, or who have chosen not to breastfeed for other reasons (Burns et al., 2010; Elmir, Schmied, Wilkes, & Jackson, 2010; Schmied & Lupton, 2001; Sheehan, Schmied, & Cooke, 2003).
Negotiating the motherhood role and expectations of self, family, friends and health professionals is therefore a complex task, and it is not surprising that women look for reassurance and assistance. Support with becoming a parent and parenting is provided by both government and non-government agencies in a number of forms. Examples of support include: antenatal classes, new parent groups, infant sleep and settling groups, infant feeding groups, toddler groups, as well as more targeted groups, such as those for women with postnatal depression. Women want to know how to care well for their child, and many women access these services. Access to the internet has provided women with the capacity to search for additional advice on websites recommended to them by health professionals, or in parenting magazines. In addition, women can access support through a range of consumer forums and online support groups, such as the ‘Australian Breastfeeding Association’ and ‘Netmums’ (United Kingdom). Women seeking support now have the potential to become mothering ‘experts’ through knowledge gained online; enhancing, or even replacing in part, the traditional role of health professionals. Support for women in the perinatal period is discussed in more detail in Section 2.3.

It can be seen that women face a range of expectations and challenges as they adjust to the role of becoming a mother. Expectations of women of themselves, family and friends, health professionals, and society in general, contribute to the way women adjust to parenting and develop confidence in their parenting choices. Common issues and concerns of ‘normal’ mothers are the basis of the experience of mothering of women receiving opioid treatment, as discussed in the following section.

2.3 The experience of mothering by women receiving opioid treatment

A broad review of the literature was undertaken to encompass women and ‘illicit substance use’ or ‘problem substance use’ due to the limited amount of research related specifically to mothering and women receiving opioid treatment. As a result, the term ‘problem substance use’ is used throughout this section to present literature relevant to the experience of mothering by women receiving opioid treatment. The limited amount of research in this area could be attributed to the possible negative impact of inclusion of data from such a socially disadvantaged group on outcomes of mainstream studies, and reports of high participant attrition rates from this group of
women (Dowdell et al., 2007). However, the literature presented in this section provides an indication of the experience of women with problem substance use in relation to motherhood and being a mother.

On one level, the experience of mothering for women with a history of problem substance use seems to be very similar to experiences of other women as mothers. The women’s primary concerns are for the health and well-being of their baby, and the hope they will be a ‘good mother’. In a study by Dowell et al. (2007), where midwives provided extended post-natal support for six months, the women viewed breastfeeding as important, and a way to demonstrate their commitment to motherhood. In addition, the women were reported as seeking assistance from services regarding any immediate concerns with the infant’s care, and medical assistance from general practitioners. Feelings of anxiety and need for reassurance that they were “doing things right” (p.5) as a new mother were similar to feelings described by women not receiving treatment for drug use as they adjusted to a new role and identity. The women were noted to be very focused on their babies, taking pleasure from knowing the baby was growing well and reaching developmental milestones. Dowell et al. (2007) emphasised that there was also no difference in the transition to motherhood for this group of women than for any other woman as a mother; the transition is “important in any woman’s life” (p.2).

Women with a history of problem substance use are however, not commonly considered to be ‘good’ mothers in our society, and linking the two pictures is an anathema to what is regarded as acceptable. The picture of a ‘bad’ mother is the identity more readily equated with women who take drugs or are receiving treatment for drug use, influencing how they are likely to experience motherhood. Banwell and Bammer (2006) discuss the community outrage in America in the 1980’s and 1990’s regarding the harm ‘crack mothers’ passed on to their babies. The societal context for drug use was not considered, and condemnation of this group of women was seen through widespread public debate. Since that time, the stigmatization of women using drugs has continued with the popular press maintaining an interest in ‘bad mother’ stories (Craig & O’Dell 2011). An example of this was provided recently with the following Sydney newspaper headline, ‘Addicts aren’t necessarily bad mothers, study finds’ (Horin, 2011).
The context and experience of becoming a mother can be far removed from the idealized norm. The literature frequently links drug use to poverty, mental health issues, domestic violence, contact with the criminal justice system, and the loss of custody of children (Buchanan, 2008; Dowdell et al., 2007; Newman et al., 2011; Polansky, Lauterbach, Litzke, Coulter, & Sommers, 2006; Powis, Gossop, Bury, Payne, & Griffiths, 2000). Newman et al. (2011) identify that women with a history of problem substance use may have had their mothering previously interrupted due to incarceration and are fearful of the consequences of later contact with health services - the opportunity for a direct mothering role is not available if children are removed from their care. Judgement, stigma and discrimination are added burdens to women who are coping with the major life task of physical and psychological adjustment, and attempting to make a fresh start and a positive transition to motherhood in the context of the management of drug use.

Women receiving treatment for drug use are not immune to the additional challenges they face, and are affected by a lack of support and difficulties in meeting basic needs. In a study by Powis et al. (2000), mothers with a history of problem substance use expressed more doubts about their adequacy as mothers than other women of a similar socio-economic background. Feelings of guilt and shame (Dowell et al., 2007), particularly if their baby required treatment for neonatal abstinence syndrome (NAS) to manage withdrawal symptoms after birth, have also been articulated (Fraser, Barnes, Biggs, & Kain, 2007). It is therefore not surprising that psychological health problems, such as depression (Dowdell et al., 2007; Taplin & Mattic, 2011) and “high levels of parenting stress” (Powis et al., 2000 p.178) are associated with women mothering in the context of drug use. Domestic violence is commonly a factor in the stories of drug-using women, impacting on their ability to provide a safe environment for mothering (Buchanan, 2008; Peckover 2002). In some instances, a ‘significant risk of harm’ exists and the safety of the child is given priority by child protection services when decisions are made regarding care of the child (NSW Department of Health, 2009a).

Due to increased interest in families with a history of problem substance use by child protection services, additional ‘moral work’ is undertaken by the women to present themselves as suitable for motherhood. Motherhood provides the opportunity for a woman to review and reshape her life, with “redemption in mothering” reported by
Keys (2007) from the findings of her study on young mothers. The identity of a ‘responsible mother’ is discussed by Virokannas (2011), which is similar to the findings of Radcliffe, who states that women with a drug-user identity work to assume “an unremarkable parental identity with no concession to relapse” (Radcliffe, 2011 p.987). Attendance at appointments and engagement with services was one way in which this group of women demonstrated their commitment to caring well for their child and being more accepted as a good mother (Banwell & Bammer, 2006; Radcliffe, 2009, 2011). In the study by Radcliffe (2011), feelings of shame were expressed by the women when their actions did not match the accepted ideal of motherhood. If the moral work was incongruent with motherhood, some women also positioned themselves as good mothers in contrast to other women who used drugs (Banwell & Bammer, 2006).

2.4 Services and support for women receiving opioid treatment in the perinatal period

Supporting women in the perinatal period, including those receiving opioid treatment, is important because it is known that the care an infant receives in the early years of life has a critical impact on their future physical and emotional health. This includes development of the capacity for self regulation, language and literacy (Horowitz, Logsdon, & Anderson, 2005; McCain & Mustard, 1999; Swain, Lorberbaum, Kose, & Strathearn, 2007). Reduced stimulation and inconsistent parenting responses, especially in the first three years of life can affect neural development and increase the risk of later mental health problems (Barnett, 2005; Stevenson-Hinde, 2007; Wilkinson, 2004). As discussed in Section 2.2, women receiving opioid treatment in the perinatal period are known to have additional psychosocial risk factors that increase their level of vulnerability, and impact on parenting capacity (Dawe, Frye, Best, Moss, & Atkinson, 2007).

Women receiving opioid treatment have access to support in the perinatal period from drug and alcohol services as well as maternity and child and family health services. In addition, women may receive support from non-government services, however this was not included in the review of the literature for this study. The
broader support provided by health services will be discussed first, followed by a review of support provided by drug and alcohol services in the perinatal period.

2.4.1 Health service framework for supporting women in the perinatal period

A number of agencies may be involved in providing support to women receiving opioid treatment following an initial comprehensive assessment of their needs (Commonwealth of Australia, 2006). In order to understand the support available to women receiving opioid treatment, it is useful to be aware of the framework for the provision of health care in the perinatal period in New South Wales (NSW). The ‘Supporting Families Early’ (SFE) package (NSW Health 2009) consists of the following three documents:

- ‘Maternal and Child Health Primary Health Care Policy’,
- ‘SAFE START Strategic Policy’; and
- ‘SAFE START Guidelines: improving mental health outcomes for parents and infants’

SFE policies and guidelines emphasise the importance of early intervention and prevention, the parent-infant relationship and working in partnership with families to better respond to their needs and improve physical and mental health outcomes. Of particular interest to governments is school-readiness, and reduced rates of child abuse and neglect. These initiatives are in line with national and international government strategies such as ‘Sure Start’ in the United Kingdom (Katz & valentine, 2009).

The ‘Maternal and Child Health Primary Health Care Policy’ describes three levels of care and service responses on a continuum of care from pregnancy to early childhood. A key component for determining the ‘Level of Care’ is a comprehensive assessment of psychosocial issues, vulnerabilities and strengths. The assessment is conducted as early as possible in the antenatal period, preferably within the first 10-14 weeks of pregnancy, as well as at the ‘universal health home visit’ (UHHV) after birth. If indicated, the assessment can also be completed at any other time. The level of care and service response is determined by review of risk and protective factors, and is categorised in the following way: Level 1 – no specific risk factors or
vulnerabilities: universal/routine services, Level 2 – risk factors such as young mother, mild or moderate anxiety or depression: prevention and early intervention support and services, and Level 3 – risk factors including diagnosed mental illness, problematic substance abuse or parent/carer on the opioid treatment program, domestic violence, and/or family known to child protection services. It is known that there is an increased risk of child abuse and neglect where families have limited support and a high level of risk factors.

Women with a high level of vulnerability and complex needs (Level 3, and some Level 2) require a co-ordinated team management approach with involvement of specialist health services and programs, such as ‘Drug Use in Pregnancy’ programs. Multidisciplinary case discussion determines the level of care and service response, and is an important component of providing an appropriate level of care to meet the individual needs of the family (NSW Department of Health, 2009b). Health professionals have a mandated responsibility to report risk of harm to child protection services, as described in the current policy document ‘Keep Them Safe: A Shared Approach to Child Wellbeing 2009 – 2014’ (NSW Department of Health, 2009a), and as legislated in the ‘Children and Young Persons (Care and Protection) Act 1998’ of NSW. The safety of the child is paramount.

2.4.2 The role of midwives and child and family health nurses in providing support

Midwives and child and family health nurses play an important role in the implementation of the ‘Supporting Families Early’ policy and other similar policies in Australia and internationally (Schmied et al., 2008). Care provided during pregnancy, birth, postnatal and in the early childhood period (0-5 years), is based on a primary health care approach of working in partnership with women as they move through the normal life events of childbearing and parenting. The scope of midwifery practice, and child and family health nursing practice not only includes supporting the physical health of women, but also the psychological well-being of the woman and family (Briggs, 2007; Kruske, Barclay, & Schmied, 2006; Schmied et al., 2008). Midwives and child and family health nurses are well placed to identify and respond to the needs of women who are vulnerable and in additional need of support, such as those who are receiving opioid treatment.
In Australia, child and family health nurses have utilised the Edinburgh Depression Scale (Cox, Holden & Sagovsky, 1987) as a screening tool for some time. Use of the Edinburgh Depression Scale as a component of psychosocial assessment assists in the early identification and support of women with perinatal anxiety and depression. This is particularly important for women with a history of problematic substance use, as they are known to be at greater risk of depression and other mental health issues in the perinatal period than women in general (Taplin & Mattic, 2011). It is consistently noted in the literature that women most in need of ‘help’, for example due to their social disadvantage, history of problem substance use, unplanned pregnancy, and mental health issues, are the most reluctant to access support and health care for themselves and their infants (Bartu, Sharp, Ludlow, & Doherty, 2006; Doggett, Burrett, & Osborn, 2005; Dowdell et al., 2007; Schmied et al., 2008).

Women are more likely to engage with services and utilise support where a positive and connected relationship has developed with clinicians who are responsive to their needs (Jack et al., 2005; Lefebvre et al., 2010). Midwifery-led models of care, which aim to improve continuity of care during pregnancy, birth and in the post-natal period, are better able to respond to the needs of women who may require additional support. Making contact with women and the establishment of a relationship following birth and discharge from hospital is recognised as being challenging if families are uncertain of the child and family health nurses’ role. This is especially the case if they have previously had a negative experience of health services, and/or are concerned about the mandated ‘surveillance’ role of health professionals (Peckover, 2002). Antenatal contact with women with complex needs can assist in developing trusting relationships which are more likely to extend into the postnatal period (Barlow, Kirkpatrick, Stewart-Brown, & Davis, 2005; Fraser et al., 2007; Kemp et al., 2006; Patterson, Diguisto, Lord, & Lamb, 2003). This strategy assists in the transition from hospital to community based services, when women with complex needs may ‘fall through the gaps’ at a time when they are most in need of support (Rodrigues & des Rivieres-Pigeon, 2007; Schmied et al., 2008).

2.4.3 Support provided by drug and alcohol services

A ‘Drug Summit’, organised in 1999 by the NSW government, and National Drug Strategies (Commonwealth of Australia, 2011) have raised awareness of the impact
of parental problem substance use on children. In the United Kingdom a landmark report, ‘Hidden Harm’ (ACMD, 2003) documented concerns and made recommendations to make visible the risks and poorer outcomes for children in the care of parents involved in problem substance use. Strategies for improving access to support in the local community were put in place, and a review undertaken three years later (ACMD, 2007) highlighted the challenges of providing support to families with multiple issues. Collaboration between service providers was noted to be an essential component of responding to the needs of families with problematic substance use. This element of providing support was incorporated into Australian guidelines for providing care to women in the perinatal and early childhood period (Commonwealth of Australia, 2006).

Women receiving opioid treatment in the perinatal period are primarily under the care of drug and alcohol services. They may have already been receiving treatment and support when they became pregnant, or pregnancy precipitated the referral to drug and alcohol services. In either case, the women are required to attend an opioid treatment clinic on a daily basis and agree to urine drug screening to monitor their compliance with the program, and identify any increased risk to their unborn child. In Australia, continuity of care and carers is considered to be best practice for all pregnant women with a multidisciplinary team approach to care for women with complex needs, including those receiving opioid treatment (NSW Health, 2006; Schmied et al., 2008). Public opioid treatment clinics provide a case management approach and women are referred to a range of services dependent on their individual need. This may include referrals to a psychologist or psychiatrist and to services to address housing or financial difficulties.

In the past drug and alcohol services, maternity care, and child and family health nursing services have generally been provided separately to families. More recently, integrated or collaborative models of care in pregnancy and after birth are developing, with the aim of reducing barriers to access health and support services for women with a history of substance use (Lefebvre et al., 2010). The 2004 United Nations Report, ‘Substance Abuse Treatment and Care of Women’ states, “ideally services should be accessed through a single site” (United Nations, 2004) to improve outcomes for women who are pregnant or who have children in their care. Throughout the available literature there is little discussion comparing integrated or
non-integrated programs, and the impact on outcomes for the infant or child. The meta-analysis of 21 studies demonstrated a small positive effect on mental health (Niccols, Milligan et al., 2010) and a reduction in the level of substance misuse (Milligan et al., 2010). The benefits of the integrated programs for children were not reported. In 2007, a national survey of services in Canada providing substance use treatment to women, identified that approximately half of the respondents were offered a pregnancy, parenting or child-related service, with the majority of services delivered by way of external referrals. However, “very few agencies provided any services for children under five years” (Niccols, Dobbins et al., 2010 p.313).

Access to child and family health nursing services onsite at opioid treatment clinics has been the subject of a review of early childhood and parenting services in a Sydney area health service. Harvey et al. (in press) noted that nurses and other health professionals regarded on-site child and family health nursing services as a useful strategy to reduce access difficulties for women receiving opioid treatment. A trusting relationship was found to develop when there had been a level of antenatal contact by a child and family health nurse, and/or if increased opportunities for engagement had occurred, for example during the dispensing of pharmacotherapy, or home visits in the post-natal and early childhood period.

Women with problem substance use do not typically access support provided through conventional parenting groups or other mainstream services (Schmied et al., 2008), and work has been undertaken to address this issue. An individualised parenting program for multi-problem high risk families, the ‘Parents Under Pressure’ (PuP) program has been developed in Queensland, Australia to provide support across a variety of areas that impact on family functioning. A randomised controlled trial of the ‘Parents Under Pressure’ program, with parents who are receiving opioid treatment, demonstrated a significant reduction in child abuse potential and child behaviour problems in almost two thirds of participants (Dawe & Harnett, 2007). Although the PuP program cannot provide all the answers to very complex problems, it does provide an evidence-based approach to supporting families with problem substance use to develop positive and secure relationships with their children.

Recent research in the area of child protection emphasises the multi-faceted nature of problems faced by mothers in substance abuse treatment. Taplin & Mattic (2011)
found the level and cumulative effect of additional psychosocial risk factors is more strongly correlated to child protection risk than is the level of substance abuse. These findings highlight the need for an integrated approach to care and support that includes management of underlying mental health issues and increasing social support. Health professionals aiming to support women require a high level of skill in working in partnership with families, the ability to collaborate within multi-disciplinary and multi-agency teams, and support for themselves to fulfil their role. Access to clinical supervision is an important component of providing care to families with complex needs (Harvey et al., in press; NSW Department of Health, 2009b).

The following section reviews what is known about the experiences of women as they come into contact with health and other services in the perinatal period.

2.5 Women’s experience of receiving services in the perinatal period

The experiences of women receiving opioid treatment, of universal and targeted services in the perinatal period, are not well described in the literature. In a similar way to Section 2.2, the literature reviewed also includes the experience of services in the perinatal period by women with ‘problem substance use’ or ‘illicit drug use’.

Common elements were described regarding their experience of services and provide the basis for knowledge in this area of interest.

It is known that women with a history of problem substance use have both negative and positive experiences which influence their current and future decisions about accessing health care, and the support available for themselves and their children. The literature reviewed for the study includes the findings from a number of authors who identify that trust cannot develop when fear is not overcome (Marcellus, 2005; Peckover, 2002; Wilson, 2001). Awareness of the underlying concept of power inherent in the roles of health professionals assists in understanding the acceptance of services by families. This concept is considered in the following sections and in the discussion chapter (Chapter 7) in relation to surveillance.
2.5.1 Negative experiences of services

A number of factors are known to have an effect on whether or not services are accessed and utilised. Women with a history of problem substance use feel particularly vulnerable, and acutely aware of the surveillance role of nurses and midwives. This may result in limited opportunities for health professionals to develop a relationship and work with the women. The perspective of women with a history of drug use in the acute hospital setting was not evident in the literature reviewed for this study; however, some insight into the women’s experience of services is alluded to in a study by Fraser et al. (2007) of neonatal nurses providing care to newborns with NAS, and their parents. One nurse identified the added anxiety for parents with a baby requiring treatment for NAS, “the parents think, ‘well the baby’s gone to the nursery, and it’s started on medication, and I’m gonna be worried that I’ll never get this baby back’ ” (p.1368). Negative attitudes and judgements towards women whose babies were withdrawing, even if nurses “don’t mean to” (p.1368), were evident in the data. One participant reflected that nurses could be condescending with their judgement of the mothers, shown through negative body language and by their reluctance to communicate with the women. Although the nurses in the study by Fraser (2007) aimed to provide family-centred care in partnership with parents, this was found not to be evident, and it appears the women’s experience of care in the neonatal ward was likely to be more negative than positive.

Other authors have also highlighted difficulties that may arise in the hospital setting or after the mother and baby are discharged home. For example, Radcliffe (2011) found that separation of the mother from her baby due to the limited availability of a bed in the hospital when the baby needed to remain in NICU or Special Care, can contribute to distress, anxiety and a negative experience of services. Also, in a study of maternal engagement with public health nurses and family visitors in Canada, Jack et al. (2005) described how mothers “expressed feelings of vulnerability and powerlessness” when they allowed service providers into their home, as they recognized the power of the nurse to judge their capability as a mother and “alter family structure” (p.185). Jack et al. (2005) identify that a lack of trust can lead to “feelings of frustration, extreme stress and anger” (p.187) by women who may be unsure of the nurses’ motives.
The threat to family integrity and a ‘fear’ of nurses entering the home was previously discussed by Peckover (2002). Women may not welcome the ‘help’ and support that is generally offered in good faith, due to their uncertainty of the role of health professionals, and the meaning of ‘help’. This is encapsulated by the following quote from a woman with a history of drug and alcohol issues:

‘Though they are calling on you, and I think they are, I know they are there to help. But they are like an authority figure really. It is hard when you are talking to a health visitor to know what is confidential. You know, like, what you say. There might be repercussions about what you say later...I didn’t really know what to think. I mean, you want to be open, and get help. But sometimes you don’t want to get help, because you don’t know what is going to happen.’

(Peckover 2002, p.373)

Uncertainty of the ramifications of the assessment by the nurses was also particularly evident in a study of primary health care nurses and child protection clients (Marcellus, 2005). Marcellus (2005), found that some women viewed the offer of ‘help’ from outside agencies as “the offer of scrutiny” of the family’s care-giving, “potentially resulting in the removal of their children” (p.416). Fear of being judged as a bad mother, and particularly fear of the possible loss of custody of a child, appears to underpin the negative experiences of many women with a history of problem substance use in accessing services; overriding support with physical and psychological needs. Small studies of women with complex needs, including a history of drug use, reveal that both nurses and women ‘under surveillance’ experience the tension between support and surveillance (Barlow et al., 2005; Jack et al., 2005; Lefebvre et al., 2010; Marcellus, 2005; Peckover, 2002).

Barriers to the use of mainstream services by families with a history of problem substance use also include negative attitudes of staff, the stigma of being labelled as a ‘bad parent’ and access difficulties (Dowdell et al., 2007; Fraser et al., 2007; Niccols & Sword, 2005). Dowell et al (2007) found women did not want to engage with services that were “not very welcoming” (p.8) and where concerns of the woman were dismissed. Accessing targeted services may also be seen as an indicator of need that is stigmatizing (Avis, 2007; Banwell & Bammer, 2006), and can result in “further continued surveillance by authorities” (Banwell & Bammer
In addition, a more punitive and directive approach to care to ascertain if children are at risk, and women with drug problems are complying with certain standards of parenting care, is more likely to result in the “rejection of help offered and the potential for further disengagement” (Doggett et al. 2008, p.3).

Other barriers to engagement are related to the ability of services to respond to needs of women with complex needs in a tangible way. Some women involved in an extended home visiting program (Barlow et al., 2005) expressed that the service did not provide the practical support they needed. For example,

“...Health visitors come into your home and they say ‘how are you?’ Within half an hour they will have left your house, and you don’t know when you’ll see them again. They have nothing at their disposal to offer you by way of any practical help – why do they ask how you are?....so you shouldn’t ask people – people should not go around professionally asking people how they are to say ‘there dear, I’m sorry you feel upset’ – and they go back on with their smart life and their nice car and their nice children, and their nice home, leaving me."

‘Sandra’ (Barlow et al. 2005, p.205)

A sense of hopelessness and frustration with the situation is evident in the quote above. A lack of tenable support evoked strong feelings; potentially ‘harming’ the family, and limiting engagement, rather than providing a benefit.

2.5.2 Positive experiences of services

Despite challenges with initiating and maintaining a relationship with women in the perinatal period, the literature provides evidence that women with a history of problem substance use can have a positive experience of services. A number of authors have found the women are more likely to engage with services where a consistent non-judgmental attitude and supportive role is evident (Lefebvre et al., 2010; Polansky et al., 2006; Radcliffe, 2011). Positive and useful relationships with individual health professionals and services are experienced where mutual respect, trust, openness, good communication, compassion and empathy are shown (Banwell & Bammer, 2006; Bartu et al., 2006; Davis & Day, 2010; Dowdell et al., 2007; Lefebvre et al., 2010; Marcellus, 2005). This was demonstrated in a randomised
controlled trial of mothers using illicit drugs undertaken by Bartu et al. (2006). There was little benefit in outcomes following the actual intervention (support for breastfeeding), however the high retention rates in both the control group (86 percent) and the intervention group (93 percent), was attributed to the rapport that had commenced antenatally, and developed between the women and the researchers over a time frame of six months.

Time has been identified as an important factor in the development of trust, especially when positive contact with a service, and particular individual health professionals extends over a number of months or longer (Dowdell et al., 2007). The antenatal introduction of health professionals and services aiming to provide support in the postnatal period, have been shown to build relationships and trust between women with a history of problem substance use and reduce barriers to engagement. Patterson et al. (2003) and Harvey et al. (in press), identify that a tentative connection to women can be extended through formal and informal contact in the antenatal period. Harvey et al. (in press), found women were more at ease with a child and family health nurse postnatally, at the opioid treatment clinic, if they had previous contact with the nurse. One strategy resulting in improved engagement was the involvement of a child and family health nurse in checking methadone or buprenorphine at the ‘dosing window’. This allowed informal conversation, and increased confidence of women in talking to the nurse, which later led to opportunities to ask questions regarding parenting issues and the care of their child.

Working together towards mutually agreed goals in partnership with families is incorporated into state, national and international strategies and policies (Kruske et al., 2006). The philosophical shift to a strengths-based approach rather than providing support for families through an ‘expert’ model of care is becoming more evident. The literature identifies that women highly regard services focused on their needs; where health professionals show they are prepared to take the time needed to listen, and to allow time for the women to respond to questions (Briggs, 2007; Eronen, Pincombe, & Calabretto, 2007; Russell & Drennan, 2007). Increased satisfaction and ongoing use of services was ascribed in part to recognition of the value of the woman, “here they understand you...you’re somebody” (Lefebvre et al., 2010 p.47).
In addition, women have reported satisfaction with health services when nurses had a high level of professional knowledge, and when they were aware of other local support services (Briggs, 2007; Eronen et al., 2007; Kruske et al., 2006). Lefebvre et al. (2010) found that women with a history of drug use were more responsive if the professional knowledge of the staff was conveyed in an “informative rather than scary way” (p.47). As previously discussed, women receiving opioid treatment have the same need for parenting information as other mothers. Areas where parents generally identify the need for most support relate to breastfeeding and settling a crying baby, and parents report a preference for discussion of available options rather than directive advice (Eronen et al., 2007).

Services are evolving to better meet the needs of women receiving opioid treatment in the perinatal period. A multiplicity of appointments with health professionals to address identified areas of need or concern can be overwhelming, and an integrated and collaborative approach to care aims to improve communication and care planning. In a study by Niccols and Sword (2005), the availability of a number of services in one location, a ‘one-stop-shop’, and a co-ordinated approach to care was described as beneficial by women receiving treatment for substance use. Women often find it physically difficult to attend an opioid treatment service daily, as well as meet the requirements of follow-up appointments with prescribers, case managers, child protection workers and others involved in their care (Harvey et al., in press).

The advantage of an integrated model of care can also be related to an increased level of trust that the service will advocate and support their clients. In the study by Lefebvre et al.(2010), it was found that communication with the women was enhanced by a clear and consistent approach to care by the multidisciplinary team, increasing their satisfaction with the service. In this instance, the impact of women feeling comfortable with a service where professional relationships provided the opportunity for trust to develop allowed the women to speak openly, even to the point of “self-reporting to child protection services” (p.51).

2.6 Summary

Despite evidence to support the premise that women with a history of problem substance use may engage with health professionals if a trusting relationship is
developed, the complex issue of surveillance, and its meaning to families, remains. Fragments of women’s stories are found within the literature however there is limited opportunity to understand women’s experiences of engaging with health and other services in the perinatal period when they are also receiving opioid treatment. This in-depth study aimed to learn more about the women’s experiences, the meanings they attributed to the offer of services, and the relationships they formed. It is important to better understand how to build on protective factors and strengths - rather than the automatic labelling of risk.

A review of Australian and international literature has identified a gap in knowledge regarding the experiences of women receiving opioid treatment in the perinatal period. While it is recognised that women with risk factors identified in the antenatal period are under greater surveillance throughout the perinatal period, there is limited research describing the experiences of women as they come into contact with services at this crucial time. In this study, women were asked to tell their story of interacting with services. There were particular aspects of the women’s experiences I wanted to explore, such as the transition of care from hospital to community-based services, the universal health home visit, and collaboration between service providers in the care of the woman and family. However, it was essential not to pre-empt what was important for the women. The use of a narrative methodology for the study aimed to follow the lead of the women in telling the story of their experiences of services, and factors influencing their decision to maintain contact with services.

In the next chapter I outline the methodology and methods used in this study.
CHAPTER THREE

METHODOLOGY

3.1 Introduction

In this chapter I discuss in detail the methodology and methods selected to undertake this study. The aim of the study was to examine how women receiving opioid treatment make meaning of their interactions with health and other services in the perinatal period. It was important to find a methodology and methods that would facilitate data collection from such a vulnerable group of women, allowing participants the greatest opportunity to talk comfortably and safely about their experiences. In addition, the methods needed to be suitable for me to develop and maintain a relationship with the participants while data was collected over time.

In the first section of the chapter, the benefits of conducting qualitative research and the chosen methodology, Narrative Inquiry are discussed. The research method is then presented, including the study setting, participants, and the collection, management and analysis of data. In addition, ethical considerations are discussed, especially in light of the sensitive nature of the data, the vulnerability of the study participants, and the management of the relationship between me (as the researcher) and the participants.

I am aware my professional background as a child and family health nurse, with experience in interacting with families with complex needs, had an effect on the way I conducted the interviews, and the data analysis process. It is known that observation with ‘“nursing glasses’ instead of ‘researching glasses’”...and the ensuing risk of “cultural blindness” (Lykkeslet & Gjengedal, 2007 p.700) is common to nurses and other practitioners undertaking research. With this in mind, the chapter also includes consideration of the role of the researcher, the impact of the researcher on analysis and representation of the data, and my personal reflections on the process.
3.2 Methodology

3.2.1 Qualitative Research

A qualitative research design, rather than a quantitative or mixed method design, was chosen for the study as the research question was focused on experiences of the participants. Qualitative methodologies have their foundations in social theory and provide a framework for understanding how people act (Daly et al., 2007). This offers the opportunity to explore the “behaviour, processes of interaction, and the meanings, values and experiences” of individuals and groups (Kitto, Chesters, & Grbich, 2008 p.243). Saddler (2008), identified the use of a qualitative research design allows inclusion of “the informants’ own words to more fully understand his or her thoughts and feelings about the subject of interest” (p.74); strengthening the authenticity of the research. The subjectivity of the research participants is therefore central and valuable to answering the research question, rather than a threat to the validity of the research.

The quality and trustworthiness of qualitative research is measured differently to qualitative research, where validity, reliability and generalisability are paramount in determining its value. Kitto et al. (2008) identify the following key criteria for assessing qualitative research: rigour (thoroughness and appropriate use of research methods); credibility (meaningful, well presented findings); and relevance (utility of findings). Measurement against these criteria provides opportunities for critical analysis of the research, its relevance, and generalisability to other settings. Another factor to consider in the evaluation of qualitative research is the role of the researcher.

The issue of how the researcher represents the participant through the data included in the analysis and the final report is the subject of ongoing discussion. Differences in views relate to whether or not the researcher can, or should be distanced from the process. Husserl (1970), suggested that through the use of ‘bracketing’, where the researcher suspends their own knowledge, other understandings will emerge. Later, Mantzoukas (2004) asserted that “the researcher’s presence cannot be excluded...by ‘bracketing’, or acquiring a ‘stranger’s stance’” (p.995) but should be acknowledged, and the effect of the researcher on the study described. The challenge for the
researcher lies in managing the tension of ‘knowledge and presence’ to gain a clearer insight into participants’ experiences. Critical reflexivity, where the researcher continually critiques the research process (including reflection on their impact on the process), is recognised as an essential component of maintaining the rigour of research by narrative inquiry (Finlay & Gough, 2003; Haggmann-Laitila, 1999; Karnieli-Miller, Strier, & Pessach, 2009).

3.2.2 Narrative Inquiry

A qualitative approach allowing participants the maximum opportunity to ‘tell their story’ was required in order to fulfil the aim of the study. Literature on narrative inquiry was reviewed to determine its suitability for the study as a methodology to underpin the gathering of data and its subsequent analysis. Narrative inquiry is seen to fit the ‘post-modernist paradigm’ of the late 20th Century, where reality is based on multiple perspectives rather than the modernist assumption that truth is generated by scientific problem solving alone (Mitchell & Egudo, 2003). As a result, opportunity is given to not only explore the experience of the women, but to gain a depth of understanding regarding the meaning of such experiences, and the impact on their future engagement with services.

Narrative inquiry is an evolving and valuable addition to research methodologies (McCance, McKenna, & Boor, 2001; Mitchell & Egudo, 2003). Although it has been utilised in the areas of social sciences and psychology for some time, narrative inquiry is relatively new to nursing and midwifery research (Kelly & Howie, 2007; McCance et al., 2001). Debate continues on the use of terms and frameworks, and clarification of meaning is required rather than a presumption that narrative inquiry, narrative enquiry, and narrative analysis are interchangeable (Elliott, 2005). There is also discussion on differences in meaning ascribed to ‘narrative’ and ‘story’, where some authors use the terms interchangeably, while others consider that an individual’s ‘story’ adds layer of meaning to what might otherwise be told simply as a ‘narrative’ or recount of events (Carter, 2007; Kelly & Howie, 2007). In addition, ‘story’ may be used to describe the participant’s account of their experiences, and ‘narrative’ used in reference to sections of the transcript that meet a certain criteria (McCance et al., 2001).
Researchers also have different answers to key questions such as ‘what is a narrative and does it have a distinctive structure?’ (McCance et al., 2001; Polkinghorne, 1995; Reissman, 1990). It is suggested that the structure or elements of narratives include a requirement for a ‘beginning, middle and end’ (Carter, 2007; Polkinghorne, 1995), which Mishler (1995) suggests could be considered as “more than points in time but...‘openings' and ‘closings’ ” (p.91) that provide continuity to the narrative. Chronological sequencing of events or the consideration of a narrative in terms of its genre, for example ‘tragedy’ or ‘recount’ (Carter, 2007; Elliott, 2005) are also elements considered by some authors. There is agreement that the presence of a complicating action, moral issue or turning point is a common element of stories (Labov & Waletzky 1967, cited in Elliott, 2005; Carter, 2007). In addition, it has been identified that stories tend to be conceived through experiences of breaches or disruptions to the normal patterns of life (Bingley, Thomas, Brown, Reeve, & Payne, 2008), and “gain a particular relevance at times of life transition or change, seemingly as a way of sense-making or attempting to reshape and manage the shifting ground of our lives” (p.654). This methodological approach is therefore well suited to exploring transitions occurring for women in the perinatal period.

Narrative Inquiry provides a focus on the narrative or story of the woman, rather than on how this should be interpreted by the researcher in a framework that requires a hypothesis to be developed or tested. The story, as the object of study in narrative inquiry (Bingley et al., 2008; Kelly & Howie, 2007; Polkinghorne, 1995), provides more to the researcher than textual analysis due to its subjective interpretation of events. Carter (UWS Workshop 2008), identifies that the “story given is what the storyteller has chosen to give on a given day...stories are continuously shaped and reshaped”. It is important to recognise that the ‘facts’ of a story are subjective and may even change, according to factors such as different audiences. Determination of the ‘facts’ and ‘truth’ will always remain elusive, as any police officer will attest when obtaining statements from a variety of witnesses about ‘what happened’. The strength of narrative inquiry in the health setting is to hear the individual and collective stories of clients, to listen to what is important to them and to learn, from their perspective, what it is like to be a recipient of services (Green & Thorogood, 2004; Higgs, Titchen, Horsfall, & Armstrong, 2007).
The interview is the method most commonly used when collecting data for research undertaken by narrative methodology (McCance et al., 2001), although other creative methods of data collection, such as art and music are emerging (Bingley et al., 2008). Interviews may take a structured, semi-structured or unstructured form, with the unstructured interview providing the most flexibility for the participant to describe their narrative (Fielding 1993, cited by McCance et al. 2001). Qualitative interviews should be in the form of conversations with the participant, with several broad general questions (Green & Thorogood, 2004; Kvale, 1996; Roberts & Taylor, 1998) delivered empathetically, as opposed to numerous direct questions which may have similarities to an ‘interrogation’. As a result, greater capacity for obtaining free-flowing ideas provides the opportunity for the participant’s story to emerge.

Some studies using the narrative inquiry approach purely gather an individual’s story however this study aims to collect the stories of a number of women over a period of time. Roof (1993, cited in McCance et al. 2001) draws attention to the impact of a collection of stories by recognising the broader implications for knowledge of a particular group, “People’s stories are never just their stories. Stories connect us with the larger stories, with the cultural narratives that shape our shared meanings” (p.304). For example, the growing use of ‘illness narratives’, such as those describing the experiences of individuals through the terminal stage of life, have provided knowledge as a basis for reflection on clinical practice and improvements to care for that client group (Bingley et al., 2008).

Limitations to narrative inquiry include ‘issues of interpretation’ (Mantzoukas, 2004; Reissman, 1993), which have been described by Elliott (2005) as a “crisis of interpretation” (p.254) and the capacity of the researcher for critical reflexivity (Elliott, 2005; Reissman, 1993). The researcher becomes the story-teller, as the data is analysed, and the findings are discussed and presented (Karnieli-Miller et al., 2009). What is the commitment of the researcher to tell the story of the participants, instead of providing an interpretation that is inconsistent with the participant’s interpretation of events and experiences? Researchers become narrators, who must convince and persuade their readers, and the temptation to ‘tell a good story’ must be overcome (Carter, 2007; Elliott, 2005).
In addition, the quality of the research is dependent on the establishment of an honest and open relationship between the researcher and the participant. Researchers are moving away from an earlier view that the researcher and subject are mutually exclusive to a recognition of the interdependence, and even ‘partnership’ (Karnieli-Miller et al., 2009) that is required for a qualitative methodology to be effective. While the early development of a positive relationship between the researcher and participant is beneficial to the research process, difficulties may be encountered if the researcher has inadequate skill in conversational and interviewing approaches (Green & Thorogood, 2004; Kvale, 1996). Participants with ‘chaotic’ lives may also find it challenging to verbalise their story and reflect on its meaning. Finally, it is recognised that the ‘power’ implicit in the role of the researcher, may limit interaction between the researcher and participant and the story that is able to be told (Higgs et al., 2007; Karnieli-Miller et al., 2009).

3.3 Method

3.3.1 Research setting

The study was conducted within a Sydney metropolitan Area Health Service (AHS), which is comprised of a diverse population, including families from low socio-economic and culturally and linguistically diverse backgrounds. Approximately 18,000 births occurred within the AHS at the time of the study, a number which has continued to rise due to a continued increase in housing, and subsequent population growth of young families. At the commencement of the study, the AHS had five public hospitals providing maternity services within its boundaries, with three of the hospitals functioning as teaching hospitals for Sydney universities. These hospitals continue to provide care in the acute setting however the AHS has subsequently been restructured and divided into two local health districts.

Opioid treatment and support was provided to the women participating in the study through a community based and publically funded drug and alcohol service. The five opioid treatment clinics provide case management and access to a multidisciplinary team of health professionals. At four of the five clinics, this included access to a child and family health nurse on site either as staff member of the drug and alcohol service (one clinic), or in a partnership with community health
services. The child and health nursing service is co-located with the opioid treatment service at one site, and a child and family health nurse from community health attends the other two opioid treatment clinics once a week or once a fortnight. As with all women discharged from hospital following the birth of their baby, women receiving opioid treatment are referred to community health services for the offer of a universal health home visit by a child and family health nurse (NSW Department of Health, 2009). A prioritised response is made to the referral due to the identification of the increased level of vulnerability of women receiving opioid treatment.

3.3.2 Recruitment

The support of the drug and alcohol service for the study was essential and invaluable to the recruitment phase of the study. Drug and alcohol staff members were central to the process of informing clients about the study, and inviting them to consider their participation. The development of a level of trust between the women and staff at the opioid treatment clinics enabled the study to be introduced to prospective participants in a positive way, and less readily dismissed. Approval of the study by the Human Research Ethics Committee of the AHS required that an employee of the AHS be included as a co-investigator for the study at each site (see Section 3.3.6 for additional ethics requirements). Consultation with the Acting Director of the Drug and Alcohol Network identified Nurse Unit Managers (NUMs) of the five opioid treatment clinics as the most appropriate staff to be nominated for this role. An individual meeting was subsequently held with each NUM to discuss the study and strategies for communicating information with staff. Involvement of the NUMs was an important component of the recruitment phase of the study, as they were able to respond to questions from staff regarding the study’s aim and recruitment processes, and be a recognized AHS contact. The NUMs also provided assistance in arranging a private space within the clinics for interviews and their positive response to the study and ongoing interest met my needs for support in the recruitment phase and later with data collection.

Preliminary meetings with staff of the opioid treatment clinics occurred prior to any contact with potential participants in the study. A meeting and informal
conversations at each of the opioid treatment clinics provided the opportunity for staff to gain an understanding of the aim of the study and for me to enlist their support in the recruitment phase. Each opioid treatment clinic received an information folder which included the study’s purpose, participant brochures (see Appendix 3), a flow chart of the recruitment process (see Appendix 4), participant information and consent forms (see Appendix 5), and my contact details. As well as keeping information and forms for the study in a central place for easy access, staff unable to attend the preliminary meeting could also obtain an overview of the study and be aware the recruitment process.

Challenges to recruit and retain participants in the study were expected. Strategies to manage difficulties in the arrangement of interviews with potential participants were discussed with drug and alcohol staff, and incorporated into the recruitment process. For example, a ‘Consent to Approach’ form (see Appendix 5) was developed to provide agreement for me to be informed of the client’s name, phone contact details, and the best days/time to make contact with the client. The drug and alcohol staff suggested that the form also include an additional section where potential participants could agree for drug and alcohol staff to provide me with new phone contact details. This suggestion was based on their more in depth knowledge and experience of working with women receiving opioid treatment; contact phone numbers can frequently change following disconnection due to inadequate funds or loss of the phone. The women who enrolled in the study did not have any concerns about agreeing to this strategy and access to changed contact details was particularly useful in organising the second interview, which took place two to six months after the first interview.

A colourful A3 sized poster (see Appendix 2) advertising the study was displayed in the waiting room of each opioid treatment clinic and brought to the attention of potential participants by drug and alcohol staff. Where some interest was shown, an A5 sized participant brochure (see Appendix 3) was given to the woman. The use of colour and attractive graphics used in the poster and the participant leaflet was a strategy to gain the attention of potential participants. The women were invited to ‘Tell your story’ in line with the narrative methodology and simple language was used to describe the purpose of the study, the two interviews with the researcher, any risks or benefits, and confidentiality/privacy. Following agreement for contact, I was
able to either speak to the women in person at the opioid treatment clinic, or on the phone, to answer their questions and personally invite them to participate in the study (McFarlane, 2007). Prior to data collection a detailed participant information sheet was provided and the consent form signed. The participant information sheet included information regarding the provision of a Coles Gift Voucher to the value of $20 following each interview in recognition of the woman’s time. This had ethics approval and is discussed further in Section 3.3.6.

The women were recruited from three of the five opioid treatment clinics. At the time of the study one of the two remaining clinics had no women who fitted the selection criteria, and at the other clinic no women volunteered to participate in the study from a small number of possible participants. The initial aim to recruit between six and ten women in the study was achieved as six women volunteered to participate in the study, allowing adequate data for analysis commensurate with the requirements of a Master (Honours) degree.

3.3.3 The participants

Women were recruited to participate in the study based on the following selection criteria:

- Receive/d antenatal care at a public hospital in the Area Health Service
- Will/did receive a first home visit by a child and family health nurse (offered to all women after the birth of their baby) in the next six months
- Attend a Methadone Clinic run by the Area Health Service (for treatment with Methadone or Buprenorphine)
- Over 18 years of age

Daly et al. (2007) states that the participants or setting should be those that most strongly provide the answer to the research question, and recruitment of participants through opioid treatment clinics, commonly referred to as ‘Methadone Clinics’, in the AHS provided the best opportunity to involve women receiving opioid treatment in the study. The study was open to women of all racial and religious backgrounds able to speak English at a proficient level, as the use of an interpreter has the potential to impact adversely on the emergence of the participant’s story.
The six women who volunteered to participate in the study ranged in age from 21 years to 35 years; three were first-time mothers and one was a grandmother. The education status of the women was not disclosed other than by one participant who stated she had commenced tertiary studies at university prior to pregnancy, which she felt unable to progress. At the time of the interviews, all the women were the primary carers for their child/children, and none were employed. Two women mentioned their hope of future employment however the financial resources of the women were not directly discussed. A level of financial hardship was implied in the presentation of most stories, although one woman with a more stable relationship (recently married) revealed the father of her baby had employment. At the first interview, all of the women were utilising public transport to attend the opioid treatment clinic and other health services. Changes in circumstances occurred for two women between the first and second interview; one woman and her partner obtained a car (with difficulty paying for running costs and maintenance) and another woman and her baby became homeless.

The participants in the study are briefly introduced below. To maintain confidentiality, pseudonyms have been used throughout the thesis.

‘Lisa’ – 35 years; mother of five children, four living – 20 years, 18 years, 17 years and 8 weeks of age; fourth child deceased from SIDS at 3 months of age; two grandchildren, 18 months and 22 month of age; homeless at second interview

(see Appendix 6)

‘Emma’ – 28 years; first baby, four weeks of age; lives with her mother; reports brother’s children are in the care of child protection services

(see Appendix 7)

‘Joanne’ – 30 years; mother of five children – 13 years, 9 years, 5 years, 2 years and 4 months of age; three eldest children live nearby in the care of Joanne’s mother under a child protection order due to previous drug use; lives with two youngest children and current partner

(see Appendix 8)

‘Kristy’ – 27 years; mother of four children, three living – 10 years, 4 years and 8 months of age; eldest child in the care of a foster family for the last eight years – regular contact; second child deceased at four months of age following suspected injury by baby’s father; Domestic violence from previous partners; separated from father of fourth child between the first and second interviews; lives alone with support from her grandmother

(see Appendix 9)
‘Nicole’ – 21 years; first baby, 3 months of age; sexual abuse from her mother’s ex-partner when ‘little’ – court case and compensation in teenage years; heroin use following the ongoing impact of sexual abuse and court case, and being a victim of a separate crime; lives with mother and step-siblings

(see Appendix 10)

‘Danielle’– 30 years; first baby, 7 months of age; pregnant with second baby at second interview; depression and drug taking following death of eldest sister from chronic disease when Danielle was a teenager; youngest sister deceased from SIDS; lives with husband, baby and husband’s mother.

(see Appendix 11)

The stories of each of the participants can be found in more detail in Appendix 6 - 11 as a set of individual stories.

3.3.4 Data collection and management

Data collection was achieved through two interviews with each woman enrolled in the study, for approximately one hour per interview (range: 24 minutes to 85 minutes). The age of the child at the first interview ranged from four weeks to eight months of age, with the second interview being completed two to six months after the first. Consideration was given to use of the woman’s home as a venue option for data collection as I am accustomed to providing support to women in their home as a component of child and family health clinical practice. This option was withdrawn for a couple of reasons. Concerns were raised that the home environment may have presented a risk to my safety, for example if any of the participants were living in a situation with current domestic violence. It was therefore decided a preferable option was to interview the women at the opioid treatment clinic they attended. The setting for data collection in a health facility also provided benefits of reduced risk of interruption and greater privacy. Five of the women agreed that use of the opioid therapy clinic would meet their needs and one woman preferred to be interviewed at her local community health centre, as it was closer to her home and more convenient. The women were advised they could bring their child with them to the interview. All but two of the women chose to arrange care of their child/children by family member or a friend.
Communication with the participants prior to the first interview was important; it provided the opportunity to listen to their questions, negotiate a suitable time and day, and also to start developing a relationship with them. At times the participants forgot about the arranged interview, and the ability to leave a voice or text message on their phone to arrange an alternative time was helpful. There appeared to be no deliberate intention to avoid the interview, but rather that more pressing issues in their lives took precedence, for example taking their child to the doctor or hospital, avoiding coming out in the heat of the day with their baby, and attending a court hearing with their partner. I was aware from discussions with drug and alcohol staff and from the literature review that data collection was likely to be challenging given the day to day impact of the physical and psychological health issues of women receiving opioid treatment and the complexity of their lives.

Data collection was frustrating at times, particularly when the participants did not attend at the agreed time/day for interview. Knowledge that the nature of research with this cohort of women can be difficult assisted me to respond accordingly, for example by remaining patient with the process and showing empathy towards the women. The benefit of understanding the constraints of the participant was later evident. For example, I received the following text from one of the participants I was having difficulty contacting,

‘sorry i missed ur call again sue I have phone on silent with bubs. If you are free about 330 that should be fine’ [to phone back]

This response was a reminder not to make assumptions about why I did not receive return phone calls. At the first face-to-face meeting for the initial interview, participants were appreciative if alternative arrangements had been made, and this provided a positive basis for the commencement of the interview. In addition, two of the women contacted me prior to their second interview to inform me of the need to change the day/time rather than me needing to follow them up. To me this was an indication of mutual respect and an indication that the women genuinely wanted to participate in the data collection process.

Each interview was digitally audio-taped with the consent of the woman, to ensure that data was gathered in its entirety for transcription and analysis. The interviews comprised of a series of broad open-ended questions to enable the women to tell their
story of their experiences of services with minimal interruption. As a means of leading into the interview and to obtain some demographic information, I asked the woman, “Can you tell me who is in your family?” and requested their assistance as I attempted to draw their ‘family tree’. The women responded positively to this request, and it was an opportunity for them to tell me what they chose to reveal about their past as well as their current family situation. The stories told during production of the family tree were significant and important to the data collection process as they provided me with a greater understanding of the participants’ history and later of their stories of experiences of services in the perinatal period. It also helped them, and me, to settle into a conversation together that felt comfortable and conducive to the telling of other parts of their story.

After completion of the family tree, most of the participants asked, “What do you want to know?” The following key prompts, included in the ethics application, were used to facilitate discussion and the telling of their story where needed:

- What was it like when you first booked into the hospital to have your baby?
- Can you tell me about your experience of the care you received from staff when you were pregnant and when you had your baby?
- How was going home from hospital with your baby?
- What was it like when a child and family health nurse came to your home after the birth of your baby?
- What makes it easier or harder for you to get help from a child and family health nurse and other health professionals?
- Can you tell me about having a number of people and services involved in your care?

In line with the narrative methodology, these minimal prompts were used to gather data from the women’s experiences across the perinatal period; the stories did not necessarily remain in chronological order and questions were only introduced to clarify and obtain more detail, following the lead of the participant. Limiting the number of direct questions also allowed the participant’s story to flow freely and the meaning of their experiences to be told. Towards the end of the interview, a brief summary was provided back to the participant of my understanding of information
provided regarding events or interactions that facilitate or act as barriers to engagement with services.

Field notes were written before and after each interview as a reminder of key things for me to consider and as an additional means of data collection, allowing my observations to be recorded (Green & Thorogood, 2004). A record was kept of steps taken to organize interviews with the participants and whether or not the interviews were deferred for any reason. The field notes included my observations during each interview which could not be adequately described by analysis of the interview transcript alone, such as the use of body language. I also recorded my reflections, both immediately after the interview and thoughts that came to me later, and these assisted in later analysis of the data.

An example of use of my field notes can be found in the interviews with ‘Lisa’, following her disclosure that her fourth child had died from SIDS. My field notes at the end of the first interview included reflections about my response to hearing this part of Lisa’s story, “I felt sad…as a mother I could only imagine the pain and distress that must have caused”. Prior to the second interview I included a question in the field notes as a prompt for me related to the death of Lisa’s baby, “Can you tell me more about what happened when your baby passed away?” I chose not to explore this in the first interview with Lisa as I felt it would break the flow of her story at a sensitive time. However, I hoped to have an opportunity in the second interview to explore Lisa’s experiences with services when her baby died, “What support was provided and what did that mean to Lisa?”

At the completion of each interview the audio recording was immediately ascribed a number and a date so it was not identifiable by the participant’s name. Transcription of the audio recording occurred as soon as possible after each interview, and pseudonyms were used to de-identify the women. In order to maintain time frames for the data collection process all but one of the interviews were transcribed by a professional transcription service. I undertook the transcription of one interview to gain experience of the process and also carefully reviewed all the transcriptions for accuracy in comparison to the audio recording. Reviewing the transcripts and audio recordings also provided the opportunity to reflect on my use of prompts and more direct questions and how that influenced the data collection process. On a couple of
occasions, I noted that I asked a leading question for example, “So, it’s good to have some family around, isn’t it?” however, generally the interviews were conducted in a way that did not presuppose the emerging story and instead responded to the lead of the participant.

Further reflections on data collection and analysis can be found in Section 3.3.7

3.3.5 Data analysis

Data generated from the interviews was analysed to determine the individual and collective stories of the participants. Firstly, I listened to the audio-tape of each interview to connect with the participant’s story while reading the interview transcript. Rereading of each transcript continued until I was completely familiar with the data. Haggman-Laitila (1999), describes the “crucial” importance of the researcher’s “open and questioning attitude” (p.17) to interpreting the stories of participants during this process, and this was my aim. Observation of similarities and differences in the stories of the participants provided the basis of further analysis of the data. In order to preserve the essence of the story, a decision was made to manually analyse the data rather than utilise a computer software programme, such as NVivo. This decision was also influenced by the number of interviews to be analysed, and the time required for me to become proficient in the use of NVivo.

The analysis of the data included consideration of structural elements and emerging patterns or themes in the each participant’s story common to the narrative inquiry framework. For example, as discussed earlier in Section 3.2.2, there was chronological ordering of events and experiences, a ‘beginning, middle and end’ or ‘openings and closings’ to the women’s stories (Carter, 2007; Mishler, 1995; Polkinghorne, 1995). The review of literature led me to consider some pictorial representations of stories during the analysis phase, such as a patchwork quilt (where stories are overlaid) and a rhizome bulb (where ‘buds’ of stories begin and may come to an end, or continue as the main element of the overall story). This broadened my approach to analysis of the data and helped me move beyond the more obvious assessment of elements such as chronological order and towards analysis of what was said and the meaning ascribed to it by the women.
Understanding other elements commonly accepted as inherent in narrative analysis such as the turning point of the story, and the moral issue or dilemma embedded in the story (Overcash, 2003; Radcliffe, 2011; Reissman, 1993), was central to subsequent analysis of the data. It caused me to stop and consider not only what was said but what was left unsaid in the women’s stories, in a similar way to what might occur during a stage production, where only the ‘front-of-house’ part of the story is seen by the audience. In addition, the genre of the women’s stories could be described fitting the category of ‘tragedy’, and although there were tragic circumstances in the women’s histories and difficulties to overcome, overall the stories were future orientated and could be considered to be inspirational.

Patterns to the women’s stories emerged quickly from the data, however I struggled through the process of separating out ‘themes’ and considering how best to present the analysis of the data in the study findings. The two main themes from the data were closely interwoven throughout the women’s stories and a strategy to preserve the meaning of each story told by the women was to present both a collective story (see ‘Nina’s Story’, Chapter 4) and include a synopsis of their individual stories (see Appendices 6 - 11). This gave me a sense of freedom to then respectfully unpick the women’s stories and come to a more in-depth analysis of themes. Two significant themes emerged which are predominantly presented in separate chapters. Firstly, the theme of judgment is discussed in Chapter 5, ‘Methadone Baby’, followed by Chapter 6, ‘Being a good mother’ where the theme of hope is considered.

3.3.6 Ethical considerations

Deliberation of ethical considerations was a prerequisite to the recruitment of participants, and care was particularly required as the participants of the study are considered to be part of a ‘vulnerable’ population. Green & Thoroughgood (2007) raise the ‘four principles’ identified by Beachamp & Childress (1983), as the basis of ethics in health care – autonomy (respecting the rights of the individual); beneficence (doing good); non-maleficience (not doing harm); and justice (particularly equity) and these principles underpinned questions asked in the National Ethics Application Form.
Approval for the study to proceed was granted on 4 September 2009 from the Human Research Ethics Committee (HREC) of the Area Health Service, and subsequently from the University of Western Sydney Ethics Committee. As part of the application for ethics approval a ‘Site Specific Assessment’ (SSA) application was prepared for each of the five recruitment sites. The Nurse Unit Manager of each opioid treatment clinic was included in the appropriate SSA as the co-investigator for the study, and the ‘master version’ of all documentation was individualised for each site. This included stating the specific contact person within the AHS for the management of any complaints about the study, as it varied according to the clinic’s geographical location and reporting system.

The principles of informed consent and confidentiality were key elements in ensuring that the rights of individual participants were protected. Information was provided to the participants, both verbally and in writing, regarding the purpose of the study, and their freedom to participate and withdraw from the study at any stage without any adverse effect on their present or future provision of services. Use of the data for future publication was also disclosed and agreed to by the study participants. Data collected from the interviews and field notes was stored in a locked filing cabinet and password-protected computer.

Careful consideration was given to determining the risks and benefits associated with undertaking the research, including the potential for harm, discomfort or inconvenience to participants. While it was expected that the risk of physical harm would be minimal, the risk of psychological harm was present as the participants were asked to tell ‘their story’, providing the potential to raise feelings of distress and exacerbate their already vulnerable position. Three of the women did become visibly upset when telling parts of their story. As planned, this was managed by providing empathy and allowing time for the participant to resettle themselves with the option of discontinuing the interview and/or withdrawing from the study. All three women chose to continue with the interview and were also offered, but declined, further support through local counselling services. At the conclusion of the initial interview all the participants indicated they were agreeable to participate in the second interview, which provided some indication that having someone interested in their experiences was a positive experience overall (Green & Thorogood, 2004).
Participants were treated with respect and approached with a non-judgmental attitude. In recognition that participants’ time and knowledge is of value, a ‘Coles’ voucher was provided at the end of each interview (to the value of $20). It was considered that use of a voucher was preferable to a cash payment for this participant group and it was suggested the women might like to use the voucher to purchase something for themselves. Potential participants were not aware of the voucher from the information on the poster and participant brochure, to eliminate an inducement to participate in the study. The women appeared to be genuinely surprised and pleased when the voucher was presented as an appreciation of their participation in the study.

3.3.7 Personal reflections

Ethical considerations underpinned my role as the researcher and the impact I had on data collection, and the research process. I was particularly aware that my interactions with the participants should be respectful. Care was needed in order for the principle, ‘do no harm’ to be upheld as I was collecting data from participants with a range of identified vulnerabilities. Critical reflexivity was also an important component of the study’s methodology, because my interactions with the women including the questioning style of the interviews, was integral to the data collection process. I felt the weight of this responsibility, and was aware that I took particular care with my initial contact with the women. I was mindful of listening carefully to their questions about the study, and of introducing myself and the study to them in a respectful way. I endeavoured to demonstrate, both verbally and non-verbally, a non-judgmental attitude and my genuine interest in hearing their story, in order to gain knowledge and improve care. My awareness of the researcher’s role, in allowing the women’s stories to emerge through the use of a narrative methodology, caused me to feel a little anxious at the beginning of the first interviews, even though I have a level of professional skill in communicating with families who are vulnerable.

On reflection, my feelings of anxiety diminished once the interview had begun and a relationship with the participant started to develop. In my clinical practice, I can also have some feelings of apprehension when I meet a new client for the first time and I was conscious that the similar use of empathy, and listening and responding sensitively also assisted in a positive response of the women to the data collection
process. I found drawing the women’s ‘family tree’ to be a helpful introduction to the first interview and noted a shift of power as the participant became the ‘expert’ in describing their family to me. This had the effect of setting the tone for the rest of the interview; the power I initially brought to the interaction as a researcher and health professional appeared to be moderated as the participants became more open and relaxed in telling their story.

Throughout the data collection process the need to continually reflect, not only after the interview, but during the interview took a high level of concentration. There were so many questions I wanted to ask and ‘leads’ to follow and it was challenging to use a minimal amount of prompts. I recall feeling frustrated in the first interview with one participant as I was distracted by the presence and needs of her baby, and was aware the interview time was limited due to her transport arrangements. The main frustration for me was that the history she shared during the drawing of her ‘family tree’ seemed to be taking too much time; I felt the need to move her on to the ‘important parts’ of her story. In the main, I resisted the temptation to do this even though I was uncertain if she would return for the second interview.

Listening to the participant’s story, and all she needed to tell me, was shown to be the basis for the second interview, where a great deal of relevant data to the aim of the study was provided. I wondered if the participant would have returned if I had introduced questions that changed the flow of the initial interview to meet my perceived ‘need’ for data collection and considered this question in light of my clinical experience with the Family Partnership Model (Davis & Day, 2010) of helping people with problems. Developing and maintaining a trusting relationship is a core component of every stage of the model where listening and exploration assists in gaining a clear understanding of the person’s construct/s. All the women in the study gave me the impression they were keen to meet with me again, which may have been in part due to the gift voucher they received at the conclusion of the first interview. However, my construct, or world view, was they gained some benefit from telling their story to someone who listened without judgment and I reflected on how elements of the Family Partnership Model (Davis & Day 2010) could be applied to the research process. I was aware that I looked forward to the second interview and the opportunity to develop the relationship further and felt some regret at the conclusion of the second interview as the research relationship ended.
As previously mentioned in Section 3.3.5, analysis of the data and representation of the findings was challenging, and it took me a lot longer than I expected. Looking back, I think I found it difficult to ‘let go’ of the relationship I had developed with the women, continuing to picture them in my mind and use their actual names as I considered similarities and differences to their stories. In some way this assisted the analysis process, however in other ways it may have been a slower route to stepping back and seeing the bigger picture emerging from the data. I wondered if the use of pseudonyms earlier in the process could be more effective, or if use of the women’s actual names at the commencement of the analysis was more worthwhile as it helped me to maintain a connection with the women and their story. This is something requiring additional reflection if I undertake any further research using a narrative methodology. It would also be interesting to ascertain if data analysis using a computer software program would find the same themes from the data.

As I write this section further reflection has caused me to realise that my story as the researcher also has a turning point - analysis of the data, and a moral dilemma - how to represent the data in a way that is true to the stories of the women? I have an obligation to not abuse the research relationship as I share the findings of the study in a public way. Although the data has been de-identified, I feel cautious about disclosing the women’s personal stories and thoughts as I feel close to these women and would not want to betray their trust. The need to carefully consider which parts of the women’s stories to present in the study findings is described by Carter (2007) as a “moral choice”. The data contains elements of both positive and negative elements of the women’s experiences of health services and I want to represent this balance rather than follow the temptation to put more of a focus on the negative aspects of care that need improving. As discussed by Carter (2007), the researcher has a responsibility and dilemma about which parts of stories will be told as the findings “may be used to shape and influence practice” (p.1065).

I found it much more difficult to analyse the negative experiences of the women and to consider how I would present the data in a way that was helpful to the reader and a means to improve professional practice and service systems. I expected to hear stories of judgement, but at times it was uncomfortable hearing how the women perceived their interactions with some health professionals. As a health professional myself, I felt criticized, and even embarrassed at times, even though I was not
personally responsible for the negative experiences of the women. The reverse was true when the women spoke of their positive experiences. I enjoyed the ‘good news’ components to their stories and these findings were easier to present. I intuitively wanted to balance any negative findings with the positive, now realizing that in presenting the findings I have followed the pattern of the women’s stories where judgment and hope are often found side-by-side.

3.4 Summary

The qualitative methodology utilised for this study has been shown to be appropriate for the purpose of listening to the perspective of women receiving opioid treatment. Narrative Inquiry has provided a relevant theoretical framework for the study as it has allowed consideration of individual and collective stories of the women. This chapter has explained the method used for the study in detail, and attempts to clearly portray the steps taken in recruitment, data collection, and data analysis. Ethical considerations and my personal reflections are openly discussed, in order to demonstrate the level of critical reflexivity incorporated into the study. This chapter includes a brief introduction of the six participants. Pseudonyms have been used throughout the study to protect the privacy of the participants, and a more detailed account of their individual story is available in Appendices 6-11.

As indicated in the introduction, the following three chapters present the study findings.
CHAPTER FOUR

FINDINGS

This chapter is the first of three chapters presenting the study findings following collection and analysis of the data, as described in Chapter 3. A combined narrative, entitled ‘Nina’s Story’, found in this chapter brings together data describing the experiences of all the participants of seeking and or receiving services in the perinatal period. In some interviews there was more of a focus on a particular aspect of the participant’s experiences, for example their time in hospital, and have been integrated into the larger story. ‘Nina’s Story’, told in the first person, has been used to combine the data in a general chronological order to provide an indication of the range of the participants’ experiences across the continuum of care in the perinatal period.

In a similar way, the introduction to ‘Nina’s Story’ is a compilation of my thoughts and feelings leading up to the first interview with each participant.

Further analysis of the data with a focus on the key themes of judgement and hope are then presented under the headings of ‘Methadone Baby’ in Chapter 5 and ‘Being a Good Mother’ in Chapter 6.

4.1 Introduction to ‘Nina’s Story’

I had not met Nina in person, but I already knew something of ‘Nina’; this first meeting wasn’t the start of our relationship, but a continuation from our phone contact. I knew that she’d previously had to take her baby to a general practitioner. Nina had missed one appointment with me because she’d forgotten, and had come early that day to avoid the heat. The nurse from the methadone clinic pointed Nina out to me as she sat in the waiting room, looking aged beyond her twenty-seven years. Nina had her second baby three months ago and had agreed to meet with me
for my research study; for that I was grateful. I’m not sure what I expected, but I was not surprised by her short peroxide hair, fluorescent pink singlet top and tattoos...an outfit similar to the one I wore to my 40th fancy dress birthday party as the antithesis of how I view myself. First impressions are important, so I chose to wear something more casual than I might normally wear in my role as a Child and Family Health Clinical Nurse Consultant. My aim was to minimise any perceived authority from my role, and to respectfully listen to Nina’s story of her experience with services in the perinatal period. I knew that using a narrative methodology and following Nina’s lead in the story rather than directing it by my questions would be challenging. I was aware of my mixed emotions as I waited to see Nina after she had received her daily methadone dose, and wondered what she might be thinking as she waited to meet me.

I smiled and said ‘Hi’ to Nina as she entered the room set aside for our meeting. The initial awkwardness settled as I offered my thanks for her participation in the study, discussed her expectations of the interview, and confirmed her consent to continue. Nina had seen the posters about the study in the waiting room of the methadone clinic, and said her case worker had asked her to consider talking to me. It was both exciting and scary to be embarking on a journey over which I had little control. I imagine that Nina probably felt uncertain despite my introductory comments, and attempts to put her at ease. I suspected that Nina’s story would be a complex one and I wondered what she might tell me. I turned the audio-recorder on, and brought my focus back to Nina as I struggled to contain my thoughts.

4.2 ‘NINA’S STORY’

I wasn’t even thinking of having another baby when I fell pregnant this time. My periods had been a bit erratic for a while and it was only when my breasts started to change I suddenly considered what might be happening. I was in a panic as I had the pregnancy test; it was positive. What was I going to do? I felt guilty as I wondered what the drugs were doing to the baby. I tried to get into a rehab centre, but they wouldn’t take me because I was pregnant. Next, I considered going ‘cold turkey’, but I had nowhere to stay. There’s no way I could tell my family I was on drugs and pregnant; too much judgement, guilt and shame. Mum would be so
disappointed in me, especially after all her efforts to get me into rehab after Skye (my first baby) died. There was just no right time to tell her, so I reluctantly went to the hospital.

When I got there, everyone was concerned about the baby. I was three months pregnant and I was worried too, but I really didn’t want to take methadone. Just thinking about it now makes me teary again. Like what mother wants to make that choice of whether or not to keep her baby? I remember trying to figure out if it would be kinder to the baby if I had an abortion, but I just couldn’t do it. Even thinking that way was extremely upsetting, and I hated myself for putting my baby in that position. I’d always pictured myself as a good mother and it was hard to cope with my guilt and the judgement I expected would come from others. I just wanted to be a ‘normal’ mother with a ‘normal’ baby.

Before I agreed to go on methadone I wrote out pages and pages of questions about the effect of the methadone on the baby. They told me everything would be fine, and I wanted to believe them, but it didn’t turn out that way. They said most babies are monitored and some might need a little bit of medication, but generally everything is OK. I think they just said all that because they knew I wouldn’t start on the methadone if I knew there was going to be a bad effect on the baby. My baby ended up on bloody morphine – no one told me about that!...or that my baby would be taken from me at birth to go to NICU!...or I would be expected to leave my baby in hospital and go home two days after birth! What sort of mother leaves her baby? I didn’t expect any of that.

To begin with, the dose of methadone the doctors started me on was way too high. I felt like a zombie...a drooling mess. And what was it doing to the baby? The nurses believed me; they could see I was telling the truth. They even wrote it in my notes and tried to talk to the doctors about it. Why wouldn’t the doctors believe me? I asked them to come and see the effect the methadone was having on me, but they refused because they said they were too busy. It was like how could you possibly believe the word of a ‘druggie’; it’s not worth anything. I was so upset. Some really nice people sat down and talked with me...I think they were nurses and the social worker...and in the end I decided that I’d just do whatever was needed so I could keep my baby. The doctors said that if I didn’t take the dose they’d have to put a
report in to DoCS (child protection services), and there was no way I wanted to risk that happening.

I ended up staying with my mum after they got me started on Methadone. I had to tell mum about being pregnant, but I just couldn’t face telling her about the rest of it. Like how do you tell your mother that you’re going to have a methadone baby? It was hard making an excuse up to leave the house each day to get dosed. Eventually, I told her I had to go to the hospital each day because I was depressed; which was sort of the truth. I’m not sure if she believed me though.

For the rest of my pregnancy, I did everything they wanted me to do and there weren’t any problems. My case manager at the Methadone Clinic linked me in with some drug and alcohol people at the hospital, so that was good. I went to all my antenatal appointments and did all the urine tests and any other tests they wanted. I had to do everything I could to keep my baby. There was a lot of talk at the Methadone Clinic by women who’d had a child removed by DoCS or they knew of someone who did. It freaked me out. They said the baby was taken at birth; the mother didn’t have any say. Maybe they’d done something bad with their other children for that to happen, but I was still scared as I couldn’t be sure it wouldn’t happen to me.

Zac was born at 5.55 am on the 11 August. He was perfect. Everything was where it was supposed to be, and it was just so amazing! My mum was there, which helped a lot. I don’t know if I could have done it without her. The midwives were really lovely to me during the labour. They got me hot packs for my back and made suggestions like having a bath. I think I went through three midwives while I was there because it took so long! Then as soon as Zac was born they put him up on my chest and he started to try and have a bit of a feed.

But the next thing I knew, they wanted to take him away! Like how can you take a baby away from a mother just after birth? My worst nightmare! He was perfectly fine and there was just no reason for it. He was only on my boob for about 5 minutes before they said, “We’ve got to take him down to the NICU to get checked out”. I know he’s a methadone baby, but I’ll never understand why he had to be taken from me so soon when he was OK. Just thinking about it now makes me feel very angry and upset. I was worried that DoCS would take him from me, but now this! I lay
there wanting to be with my baby; it was all a bit surreal. Had I really had a baby? I kept asking the midwives about going to the NICU, but I’d had an epidural and had to wait for a wardsman to come with a wheelchair. I was so frustrated and stressed out! All I could do was lay there and hope he was OK.

I dozed off to sleep as I waited. Next thing, two nurses came in with a whole lot of paperwork they wanted me to sign so Zac could be immunised. It took me a while to work out what they were talking about. Like I was half asleep and I hadn’t even thought much about Zac having needles. I asked for some time to think about it but they wanted me to decide then and there. One of them said, “Well your baby needs to have it. You’ve put your baby at risk because of your drug taking behaviour”.

How she said it was just really rude and judgemental. My mum wasn’t in the room as she’d gone to NICU with Zac and I felt under attack. I think they chose to come while mum wasn’t there so they had more chance to persuade me to go with the immunisation. I told them again that I had questions and needed more information, but I think they just thought I was being a typical druggie pain in the neck, slowing them up when they were busy. I agreed to sign the forms for the needles at birth just to get rid of them, but I still wasn’t sure what I’d do later. I felt a bit bullied into signing straight away.

Going to NICU for the first time was a scary experience with all those sick babies and routines I knew nothing about. A nurse came and told me about things, but it was hard to take it all in. It seemed like a whole different world with a whole lot of rules I didn’t understand; I felt like an outsider. It was as if the doctors and nurses had all the control over what happened to my baby and the real parents were left out, trying to understand what was going on.

One of the first things they wanted me to do was sign a form so Zac could be given formula if he needed it. They still wanted me to sign it “just in case” even though I said I wanted to breastfeed. I was really upset when I came into the NICU the morning after his birth to see a tube stuck in his nose and find out that he’d been given formula! I thought I was there in time for a breast feed, but as I wasn’t there right on what they’d determined as the feed time, they gave him formula. No-one told me this would happen!
Mostly the nurses were lovely but there were a few I could tell judged me for having a methadone baby. It wasn’t as if they really said anything, because I’m sure they’d be in trouble if they did, but it was the way they looked at me, or how they answered my questions. It’s a bit hard to describe, but it was like I didn’t have the right to be a mother to my baby. I actually noticed after a while that the nurses that did judge me gave Zac a higher score for withdrawing.

The whole scoring thing was really stressful. Of course I didn’t want my baby to have morphine; I hated myself for that. But there’s no way I wanted him to suffer either! I was sure that Zac was getting way too much because he was sleeping a lot and I noticed he was a bit floppy when I changed his nappy. I talked to the doctors about it, but they didn’t believe me and just ordered the morphine according to the withdrawal score. Like I said before, the score seemed to be higher when some particular nurses did it. I don’t think they took into consideration that Zac was crying because I was having trouble breastfeeding. He was hungry and was getting confused and frustrated about having the bottle and the breast.

People tried to help me with breastfeeding but it made it worse. I dreaded their ‘help’ because I felt so stressed when they were telling me what to do and it was worse if they tried to put him on the breast. I’d end up crying and Zac would be crying and it was all just too hard. I really wanted to breastfeed, so I ended up expressing my milk for every feed and giving it to him in a bottle. At least then he would feed better and cry less so his score wouldn’t be as high and they wouldn’t give him more morphine than he really needed.

I was also stressed because I was so tired after the birth and it was hard feeling that I was ‘being watched’ all the time. I needed to make sure I did everything right so they didn’t have any reason to put a report in to DoCS about me. Other mothers could doze in the chair while they were up breastfeeding during the night, but not me. I risked people thinking I couldn’t look after my baby safely, and who knows what would happen! I remember being exhausted the second night after Zac was born and dragging myself out of bed to go and feed him. My eyes did start to close, but I realised and put him straight back into the crib so he was safe. Most people don’t know how hard it is being on edge like that when you’ve just had a baby. Your body’s adjusting to a change in the methadone dose, you’re trying to do the right
thing and all the while people are watching for you to slip up. Like what normal mother has to cope with that?

Seven days is a long time to have your baby in hospital and if most of the nurses and midwives hadn’t been nice to me, I wouldn’t have coped at all ; there were a couple of them that really helped me a lot. I was the first one to notice some signs of Zac withdrawing and I felt so upset. I was in my room in the postnatal ward crying and crying. I’d been hoping that Zac wouldn’t need any morphine, poor baby, but now he did and it was all down to me! I just hated myself. A midwife heard me crying and came and sat next to me while I tried to explain why I was upset. She didn’t say much, but she listened for ages and I eventually calmed down. It reminded me of when I told the social worker a whole lot of stuff when I first booked into the hospital. Like she understood where I was coming from too.

There was also a breastfeeding lady who came to see me when I was having all the feeding troubles. She was really nice and I could tell she knew a lot about breastfeeding by the way she explained about it. But the best thing was she showed me that Zac could find his way and get onto my nipple by himself! I’ve never seen anything so amazing, and neither had my mum and she’s breastfeed five babies. Just instinct! Knowing he could do that kept me going with breastfeeding through all the expressing and coping with everyone else’s opinion on what to do. I really wanted to breastfeed so I decided I’d do whatever I could to have enough milk while I was in hospital and then try and get Zac to feed straight from the boob when I went home.

On the whole, in hospital everyone was pretty discreet about the methadone side of things. No one yelled out in the ward, “Your methadone’s ready” like some of those mothers at the methadone clinic said they would. Mostly the nurses or midwives (I forget which ones they are on the postnatal ward) would just come and talk to me about it by myself when it was time for my dose. I was worried what other mums there would think about me, and really worried that my visitors would find out. I actually asked the nurses to make sure they didn’t say anything that would give it away, but you just never know what might happen if someone doesn’t get the message. It would have been terrible! The drug and alcohol nurses who saw me at the antenatal clinic said to let them know if I had any problems with my methadone or how I was treated. That was good to know, but I didn’t really have any problems.
It was a bit hard explaining the real reason Zac was in NICU though; I wanted to be able to tell my family but I just couldn’t do it with trying to cope with everything else.

I was back and forth to NICU so most of the time I wasn’t on the postnatal ward anyway. It was hard not having my baby with me and seeing all the other mums on the ward with their babies. I didn’t think it was going to be like that and it was disappointing and a bit strange; I didn’t feel like a real mother. Like I said, from what they told me before I went on methadone, I expected to have Zac with me because they said that he’d pretty much be fine. Then the next thing I got told was that they wanted to send me home! The story was that there weren’t any beds, but I didn’t believe that because I could see lots of empty beds. How could I go home without my baby just two days after giving birth and him in NICU? How was I going to be able to breastfeed him and look after him? They’d just got no idea! I was very upset and complained about having to leave, but they said they needed the beds and there was nothing they could do.

I rang my mum in tears and she came to see if she could help sort it out. Lots of really nice people tried to help. Like the nurses on NICU, the drug nurse, my case worker at the Methadone clinic, and even the doctor who prescribes my methadone. They all tried their best, but they wouldn’t budge! I ended up being discharged and I was angry, but I was pretty much at the hospital the whole time anyway. The nurses in NICU found me a chair and I ended up sleeping in that in a spot near the sink. It wasn’t very comfortable, but at least I could be with Zac. I felt sorry for some of the other babies whose mothers only came in once a day for one feed, or I didn’t see at all. I was grateful to everyone who tried to help me.

Taking Zac home was wonderful especially after being so worried about him in NICU. Like he still had to have some morphine, but I could have my baby with me. I had to take him back every week so his morphine dose could be changed and go for my dosing each day. I didn’t care though; I just wanted to get Zac out of hospital. Mum was a big help, I don’t know how I would have survived the first few months without her. Breastfeeding worked out in the end, but it was a really hard road to keep expressing; I did it for months. I was exhausted from trying to get Zac on the breast, expressing at night and feeding him some expressed milk in the bottle. Even Mum said maybe I should give up and Mum’s a real breastfeeding fan; she breastfed
all five children. But we got through it. The nurse who came to see me at home was a big help too, but really it was just Zac who figured it out for himself when I was so tired and couldn’t do anything. One night I just lay on my mattress on the floor and put Zac next to me. I vaguely remember being aware that he’d made his way to have a feed during the night, so he actually sorted it out by himself! After that I didn’t express at night, only during the day. I felt so much better from having the sleep and actually started to enjoy breastfeeding. He’s now just straight on the boob all the time and it’s really easy now; it’s great and I’m really glad I stuck it out.

I can see that Zac’s growing well and it makes me proud to be a good mother. I’ve taken him for all his checks with the doctor and he was completely off the morphine after a couple of months. It’s just so good to have him home and do all the normal things you do with a baby. Like going down to the shops with him in the pram; that sort of thing. The nurse who came to my home was lovely, and she weighed Zac and checked him out so I know he’s doing well. I was a bit worried about what she’d be like, because another mum at the clinic, Molly, had told me about a nurse who came to see her at home and she felt really judged.

Jenny, who came to see me at home, rang first to organise the visit. She left a few messages on my phone before we could actually arrange the day she’d come. Like I was either asleep because I’d been up half the night feeding or my phone had run out of credit. I was seeing the doctor once a week to check Zac’s dose and going to the clinic every day for my methadone dose so it was a bit hard to work out a time to fit in with that and when Jenny was available. She sounded OK on the phone, but I still felt a bit nervous about meeting her for the first time.

The house was a bit messy when Jenny came, although I did have all the baby things sorted out and everything was clean. She didn’t seem to notice the mess and just checked Zac out and talked to me about how I was going and answered my questions. She was lovely and knew lots about all the baby stuff, like settling and nappy rash and all that sort of thing. I had a couple of visits and we talked a bit about me being a new mum again and how that was going, especially after what happened to Skye. Like she was really easy to talk to; I never felt like I was being judged. Jenny told me things were going well and I felt more confident that I was doing a good job as a mum. We talked about where I could go to get help and about
the baby clinics in the area and anything I wanted to know. The only thing Jenny
didn’t know much about was the morphine for Zac. At least she was up front about it
and said I was better to ask those questions of the nurse at the methadone clinic, but
I did think maybe she should know too. I really looked forward to Jenny’s visits; it
was nice to have a nurse come to you like they do for all the other mothers.

We talked about where I’d go for follow-up for Zac’s developmental checks or if I
had questions later on. I thought there wasn’t much point going to the baby clinics
in the local area, because it was doubling up with the check-ups Zac was getting at
the methadone clinic. That would just be a waste of time for everyone, but I’m not
sure how long I can keep getting him checked out there. Jenny gave me the phone
number for the community health centre in case I wanted to book into a baby clinic
later on. When I had Skye, I went to the same nurse at a baby clinic and we got to
know each other really well. It was relaxed and I felt like I could ask her anything.
She always asked me how I was going. I suppose if the mum is coping, the baby’s
more likely to be OK. She talked to me like the mental health nurses did after Skye
died; checking to see how I was. I could tell that she was devastated when Skye died
too.

At the moment it’s good having everything in the one spot at the methadone clinic
because when you’ve got to get dosed every day it doesn’t leave much time for
anything else. I had to take Zac to my GP because he had a rash and it was just a
nightmare to fit it all in. My case manager and Belinda, who runs the baby clinic,
have been at the methadone clinic a long time. Like they’ve seen me at my worst and
they know lots about helping people like me; I can ask them anything. They know a
lot and I think they must love their job. It makes a difference when people are nice
and treat you like you’re a normal person. To get a smile and have a laugh when
you’re having a bad day helps a lot.

I don’t like taking Zac to the methadone clinic, just with the people who go there and
it’s really hot in the summer and cold in winter. All these people hang around
waiting to get dosed and it’s not a nice place to take a child with some of the
language you hear. I hope I’m off the methadone before Zac gets too old because
it’s just not a good scene and you never know what he might pick up from people
leaning over him. I don’t know how I’ll manage in the winter, taking Zac out in the
cold and waiting to be dosed. You can’t have anyone mind a place for you in the line, there’s too much bad feeling with everyone else waiting.

But another good thing there is the playgroup which is on two mornings a week. It’s on the same time as the baby clinic and when the doctor’s there. There’s a bit of an undercover area outside that’s fenced, and they use the waiting room for the doctor and the baby nurse, Belinda if the weather’s not good. It’s good to have somewhere where the kids are safe to get out of their strollers and have a play. A lot of them do heaps of travelling to get dosed and the kids are stuck in strollers for ages. There’s a child care worker and a speech therapist so they show the kids how to make things and talk to the parents about stuff to do at home.

So things are pretty good for me at the moment and I hope I can look after Zac well and keep off the drugs. My case worker told me that the aim is to keep families together and I feel better understanding that’s what they’re thinking. I’m not worried about DoCS like I was at first because I know that I’m doing everything I can to look after my baby. Having the support from my mum and from people trying to help me has got me where I am today. I’m not as angry with everyone now. I suppose I was angry before because I was angry with myself. How could I have a methadone baby?

Maybe those people who judged me had come across other women on Methadone who didn’t look after their babies properly. People like that don’t deserve to keep their baby. I’m not like that. I fought against starting on Methadone because I was worried about the baby and I knew how hard it would be getting dosed every day.

But what choice did I have? Being on the program has meant that I could keep Zac and get help. I don’t know how anyone could do it without support, but you’ve got be the one to decide to make the most of everything. I’m just learning that. I want to be a good mum, and hopefully I’ll be able to get a job one day and Zac will be proud of me. I’m so glad I had him.
CHAPTER FIVE

In this chapter, and in Chapter 6, I present the key findings of this study, detailing the two central components of the experiences of the women. Firstly, the theme of judgement is presented in Chapter 5, entitled ‘Methadone Baby’, followed by the theme of hope in Chapter 6, ‘Being a Good Mother’. Direct quotes from the data are used as headings for these chapters, and for the subsequent subheadings.

FINDINGS – ‘METHADONE BABY’

5.1 Introduction

The central theme, ‘Methadone Baby’ brings together a number of stories, and fragments of stories found in the data, which provide examples of judgement. The women’s stories focused on both self judgement and their perception of being identified as a ‘bad mother’ by health professionals, and the meaning they ascribed to being identified in this way. The chapter concentrates on understanding how judgment appeared in the stories of the women, the context, and its influence on the women’s ongoing relationship with services.

Much of the data presented in this chapter links judgement with the expectation and fear, that child protection services will be involved during the perinatal period, with the ultimate risk their child could be removed from their care at any time. The anxiety and distress resulting from judgement is conveyed in a number of the subheadings used in this chapter, for example ‘I always felt eyes on me’, and ‘Don’t take him off me!’ Direct quotes from the women’s stories are used to provide clear examples of judgment, and its impact, through the words of the women themselves. Some elements of the second major theme, hope are also found in this chapter as the women interwove hope within stories more predominately focused on judgement.
5.2 I must be a bad mother

Judgement by others, and self-judgement, related strongly to the women’s feelings of being viewed as a ‘bad mother’. All the women included feeling judged by a range of health professionals, across all stages of the perinatal period. Terms such as “drug-user”, “junkie” and “prejudice”, were used by the women to describe the stigma they felt; a stigma that remained even though they were receiving treatment. Nicole encapsulated the resultant depth of feeling and despair when she told me,

...just because I had her on methadone, like I must be a bad mother, and like don’t take any notice of me; like I don’t want the best for my child, how could I possibly love her on methadone? you know?

Nicole

Nicole was distressed when she came to this point in her story. Being judged by others seemed to reinforce her own self-judgement; methadone treatment equates to “a bad mother”. This statement, and rhetorical question, was the climax to Nicole’s extensive story of feeling judged by people, who did not seem to believe she had good intentions and could be believed. During her story, Nicole had emphasised other occasions where she did not feel valued: a judge didn’t believe her in a court case for her sexual assault as a child, a doctor didn’t believe the effect of the methadone on her when it was first prescribed, and some nurses did not seem to believe that her baby was receiving more morphine than needed. I felt Nicole’s distress of wanting to be a “good mother”; the judgement of others, and self-judgement, brought into question if she could ever be a good mother, despite her love for her child. Nicole’s subsequent distress seemed to emanate from verbalising others’ view of her as a bad mother, and as she weighed up in her own mind if this was the case.

Judgement was also a major part of the story for other participants, as described by Danielle,

I’m still hating myself, in a way, for being on it [methadone].... I was hating myself a bit. At first, I couldn’t believe that I actually was on it. But then I think, well it’s helped me to be where I’m at today.....

These people [staff at Methadone clinic] have been really good. But sometimes the doctors and that, when they know, as soon as they know
you’re on buprenorphine or methadone, they judge you. As soon as that’s mentioned they start – oh, are you on drugs, or do you drink, and they automatically assume. So I was judged a bit and that really annoyed me, because I shouldn’t let - I care what people think. But yeah, in a way sometimes it was like they were trying to say I was a bad person for being on the bupe.

Danielle

Being identified or labelled as a “bad person” or a “bad mother” was upsetting for Danielle and Nicole, as it conflicted with their idea of motherhood. They did care what other people thought, and this reinforced what they thought of themselves.

Judgement as a bad mother was brought into focus when the participants were confronted with the fact that their baby may need treatment to manage opiate withdrawal.

But also I suppose, we feel guilty about you know having a baby and they come out and they are withdrawing...I think the morphine for me was one of the hardest things; having to pour morphine down my son's throat. I can never forgive myself. I know that you have to have it there so I can give it to him. What if he has ongoing problems? When you in the position, yeah I want to have this child, you fight for anything to have that baby. You protect, fight, it's a motherly instinct to do all those things.

Joanne

All but one of the participants spoke of their concerns their baby would withdraw, highlighting its significance to them and others as an indicator of being a “bad mother”. The need for little or no treatment of their baby with morphine was celebrated. Words such as “a very small dose of morphine”; “didn’t need medication” and “didn’t withdraw” were matched to responses such as “really good”, “really lucky”, “I was rapt!”, “I was so happy”. Conversely, the baby’s need for treatment evoked strong feelings of self-judgement, rather than judgement by others.

5.3 Watch out for DoCS

The warning, “Watch out for DoCS”, was provided to one of the first-time mothers (Emma) at a methadone clinic by other women regarding the possible involvement of child protection services. This ‘catch-cry’ was not limited to Emma, or other first-time mothers in the study, but was found to be embedded in the ‘cultural’ context of
receiving opioid treatment in the perinatal period. The expectation of involvement by the NSW State child protection services was emphasised by the women who had other children, as a number of them had previously had children removed from their care. Negative experiences, relayed in the methadone clinic waiting room by other women receiving treatment, increased the anxiety of all the women in the study.

The basis of Emma’s concern was the connection between questions, increased scrutiny by hospital staff, the experiences of other women of going to hospital and the involvement of child protection services.

...Because you talk to people around here from the clinic and stuff. They all sort of tell you different things - or the same thing - watch out for DoCS. But they all did something wrong. I got really upset because I figured DoCS was going to be involved anyway - straight away - because I was on methadone. But because I haven't done anything wrong - so it wasn't like that. ...A lot of people said to me that they had bad experiences at the hospital and stuff like that. So I was worried about going to the hospital and having her and stuff like that. But I didn't have any bad experiences.

Emma

Emma revealed she was used to being asked questions about drug use and domestic violence through her experiences of ‘Drug Court’, but found it was different being asked the psychosocial questions in pregnancy. Emma described this as “a bit more intimidating when there’s someone else involved” because the questions were “all about her [baby], so I started to stress out and worry a bit”.

The stories of Joanne and Kristy included their previous experiences with child protection services, due to relapses into drug taking, and risk of harm to their children. Joanne’s three eldest children were removed from her care, as was Kristy’s eldest son, and they were aware that ‘talk’ about child protection services taking children into care could actually become a reality; “DoCS will take your baby...I know, it’s happened” (Joanne). It was this knowledge Joanne identified as the rationale for not disclosing that she had been taking some “street methadone” in a previous pregnancy.

I was scared that if I said something because I had prior DoCS involvement, I was scared they'd take him. So I lied.

Joanne
Joanne justified her action to not disclose her full history in an attempt to keep her baby. Her concern about child protection service intervention was overridden by her baby’s need for treatment when he started to show signs of NAS (“full fits”), as they were being discharged from hospital. Joanne described how she returned to the ward for assistance. The consequence of withholding information was difficult for Joanne to contend with, due to the effect on her baby.

He was really, really sick because I was lying. I remember screaming to try and get to him. They had to pull the curtains and take me out. I actually thought he was dying. I was that scared. All I could see was him fitting. They were trying to get his veins but he was so little and sick they couldn’t get any. I kept yelling out, you’re torturing him. I was just really upset.

Joanne

The reason given for using street methadone, rather than being on an opioid treatment program, was “because I think it would be easier for me to get off it because I was only using it twice, no three times a week”. The idea that not using any drugs fits better with the general picture of a “good mother, did not seem to enter Joanne’s consciousness. Joanne described how she still felt “angry” with child protection services, as they stipulated she had to consent to enrolment in an opioid treatment programme as a requirement of maintaining custody of her baby. As Joanne reflected on this episode later in her story, she eventually came to the point of accepting some responsibility for the need for treatment.

I was blaming DoCS saying they put me on it [methadone]. But I was using it already; I’m the one that put the needle in my arm. That was the choice I had to make, if I hadn’t chosen that, they would have taken him.

Joanne

5.4 Don’t take him off me!

The fear of having their baby ‘taken’ by child protection services was prevalent across the stories of the participants. Involvement with child protection services was an indication to the women that their ability to be a good mother had been brought into question in a public way. Although not directly stated, it was presented as the outcome of being a “bad mother” and linked strongly to judgement and loss of hope. Language such as “terrified”, “scared”, and “horror stories”, was used to describe the
worry and anxiety the women felt about going to hospital. They wondered if they would come home with their baby or if child protection services would intervene, and take the child from their care. Separation from their baby in hospital intensified these concerns.

Two of the women described in some detail their experience soon after birth. For Danielle, the positive birth experience was affected by the distress she felt when her baby was taken to NICU even though she had just started breastfeeding, and felt she was connecting with her baby. Nicole described a similar upsetting experience, and both women struggled to cope with their feelings and understand the rationale, as revealed in the following quotes,

*But I remember just after I had him, they put him on the nipple, like nipple at first, and then they said, oh we’ve got to take him away from you now. We’ve got to take him to the NIC Unit, and you’ve got to go up to the ward. I was shattered. I thought - I couldn’t believe it. I was a mess. I thought, you can’t take him off me; he’s not supposed to be in the NIC Unit - don’t take him off me. He’s my son, you know? Give him back! So that first night I was away from him. So that was terrible, because I’d just had him and they were taking him away from me, you know? I was so angry about that. I was trying to get up to see him, to get him, to go and do something about it.*

Danielle

*I got to hold her for a while. Then they took her down to the NICU, because she was a methadone baby... I felt really low about that because when I was pregnant and when they wanted me to go on methadone and I was asking questions about things they said you know, she stays with you and they monitor her. She only goes to the NICU if she needs to go to the NICU - so, OK. But when I had her, I just held her for 5 minutes and then they took her down to NICU...I was a bit all over the place, and I still couldn’t get up because of the epidural. They just took her down, and I really wanted to go down there, and I was sitting there for hours, and they said we’ll get you a wheelchair, I’ll get you a wheelchair; I just wanted to be with my baby. I was just sort of sitting there for hours waiting for a wheelchair to go down to be with her, which felt, it all felt a bit sort of surreal at the time.*

Nicole
The description of this part of Danielle and Nicole’s story was highly emotive and they strongly conveyed their experience in negative terms. Words such as “shattered”, “a mess”, “terrible”, “so angry”, “felt very low”, provide insight into the effect of the baby being taken away from them soon after birth. There was no indication if the midwife was aware of, or responded to the distress of the mother during the ‘taking away’ of the baby to the NICU. The stories are purely focused on the women’s perspective of the interruption to the early interaction and attachment with their baby, and the resultant distress. There is a sense of powerlessness as the women want to resist hospital processes, as exemplified in Danielle’s cry, “don’t take him off me. He’s my son, you know? Give him back!” The use of an epidural for analgesia during labour created an additional impediment for the women to go to NICU with their baby, and the time delay caused further stress.

5.5 I genuinely want what’s best for my baby

All of the women in the study made it clear to me that the well-being of their child was of primary importance to them. Joanne maintained that her intentions as a mother were good, even though her story included a component that challenged this view (see Section 5.3). Although Joanne disclosed she had “lied” about her drug use during pregnancy with her previous child, this was justified by her concern that child protection services would assume care if the truth was known. The impact on her baby influenced Joanne’s response to care provided by staff in the SCN with her subsequent baby. Joanne observed her baby closely for signs of withdrawal, and was satisfied with the early treatment he received.

In contrast, three other women had concerns that they may have been “discriminated against” or “judged” by staff in the SCN or NICU, impacting on the baby’s withdrawal score and dose of morphine. Emma, Danielle and Nicole mentioned their concern about the effect of morphine on the baby, as they felt some nurses were “scoring high” or “false scoring”, as described below by Nicole,

_I think that her dose is probably higher than it needed to be, because of that whole feeding thing. Whenever she cried when I was breastfeeding, she was getting marked for poor appetite and not being able to suck properly, and also getting marked for being unsettled and stuff; so that was bumping_
her up a few mls every time, and every time the score would go a bit higher that the dose that they had her on...

It’s not that I didn’t want her to have the medication, like I guess it’s upsetting that I had her on methadone and all that sort of thing. I would have much preferred it not, but like I said, I would have preferred her to have it than to suffer. It’s just trying to reason, reason with them just to get the honest result of what the score is meant to be. That just seemed, nup not going to have a bar of that....And then I noticed that when the nicer nurses were on and stuff, that her score would be really low, and the one’s that I didn’t really get on with the score would be really high...like I’m not in denial that I’ve had a baby on methadone, I know that, but I genuinely just want what’s best for my baby.

Nicole

Nicole did not expect her baby would be on morphine and need to be cared for in NICU. She emphasises how her advocacy for the baby is based on her concern for the best interest of the baby, not because she is endeavouring to avoid judgement. The lack of understanding regarding management of NAS was also evident in stories of other women. For example, Kristy said that she didn’t understand why they put her baby “on a set dose and [then] bring him down” rather than “give a little bit” first and progress to a higher dose if it was required. Kristy reflected, “they’d be their own reasons for that” but would have liked an explanation to understand the rationale.

Each story included an indication that the intent of the woman was always good and they were actively taking steps to limit the risk of ‘losing’ their baby. This was conveyed by the use of language such as, “I’m planning on doing the right thing” (Nicole), “I’ve been clean” (Danielle), “I’m wanting to get off methadone” (Emma) and “I was reducing, doing what I could” (Lisa). Their stories conveyed the idea that behaviour indicating they might not be suitable mothers belonged to others, “I haven’t done anything wrong” (Emma) and “they made no effort” (Joanne).

5.6 I always felt eyes on me

The stories of the women revealed that the communication of judgement ranged from more subtle “looks”, to extended narratives describing occasions where judgement
was felt to be overt. Examples of the non-verbal communication of judgement include “I always felt eyes on me...just the looks I used to get” (Joanne). Danielle and Kristy explain further,

> you can just tell.....they don’t have to say, oh I’m going to judge you because you’re a drug addict. It’s the way they speak to you and stuff. Not everybody.
> Danielle

> It is just, I suppose they are not knowledgeable enough, they just see oh Methadone, Methadone, street heroin, or this or that, junkies off their face or whatever. They get the wrong opinion and don’t understand it enough, and just walk past you and look at you like you’re a piece of crap or something.
> Danielle

...I feel like there’s a sign on my face, whenever it comes down to Methadone, or people; the way they talk. It’s like they see us as a whole different race sometimes, but there’s people that have it [Methadone], like me, and go home and look after their family. You really have to have it, because in three days time I am going to be on the bed, and sweating and hot/cold and all the rest of it, so it’s more a physical thing...you’ve got to prevent that.
> Kristy

The judgement conveyed by a “look” could be interpreted very strongly such as “junkies off their face”, with the effect of the women feeling devalued. The women conveyed to me they were trying to be good mothers, and the “wrong opinion” of them impacted on their self-worth and view of how they were progressing. Kristy refuted the idea of being part of a “whole other race”; she viewed herself as a mother trying to care for her family the best way she could. The methadone managed the physical symptoms of withdrawal so that she could be a good mother, but in receiving treatment she also felt judged.

Even when interactions with staff were positive and supportive, an underlying fear of judgment seemed to exist. The yardstick was an expectation that judgement will occur as the women are mothers of ‘methadone babies’; if this did not happen they were surprised and “grateful” (Emma). It was the women’s hope to be treated as a ‘normal mother’, and staff seen to treat them in that way were remembered and
included in the women’s stories in a positive way (as described in more detail in Chapter 6).

5.7  **We have to be so careful**

The women in the study identified that they needed to maintain a level of vigilance to limit any involvement by child protection services. The following quote from Kristy indicates the care taken to reduce the risk of a report to child protection services,

> ...so I have to keep my eyes wide open and everything, like all mothers sit down and get tired, but we have to be so careful at the hospital because somebody could come past and, you know.

*Kristy*

The only inclusion of a report to the State child protection services in the women’s stories was found in Lisa’s story. Lisa recalled the report was made by a nurse in SCN regarding concerns for the safety of her baby because she was observed going to sleep while holding the baby. She was surprised a report had been made, and denied putting her child in any danger. Lisa felt the report was an example of “discrimination” against women who were on methadone and was “not justified”. Lisa remembered feeling “overly affected” as her body was adjusted to the changes in methadone dose after the birth, but stated that although she was very tired, and did close her eyes while expressing, she had put her baby back in the cot and he was safe.

> I knew what was going on and I didn’t put him in danger. I was actually reducing [methadone dose] and trying to do what I could. There were ladies in there that weren’t on anything and they were falling asleep with their babies in their arms or expressing falling asleep and they didn’t have to go to meetings with DoCS workers or anything. If I hadn’t been on the programme it wouldn’t have been an issue.

*Lisa*

Lisa became upset when telling me this part of her story and her distress emanated from thoughts that she was judged as a “bad mother” and risked ‘losing’ her baby. She described how terrified she felt about the subsequent meeting with child protection services, thinking “they’re going to take him for sure”. She initially didn’t know why child protection services were meeting with her, and was surprised by the
report, and that no-one had spoken to her about their concerns. Underlying the frustration and distress associated with the report was the belief that it was not justified or fair; Lisa felt other women were judged differently. Looking back on this incident, Lisa reflected that the nurse who made the report probably, 

*had her own opinion on people on methadone and could do with a little bit more education.*

Lisa

The suggestion that staff should understand and be knowledgeable about methadone was mentioned by a number of other participants throughout their stories. Support from staff was linked to professional knowledge; an increased level of education implied less judgement and greater acceptance of the women as mothers. Lisa described how she would have appreciated the nurse saying “I need to report this, your child’s at risk, it needs to be reported”, so that she could “prepare” for what would follow with child protection services. During this part of the interview, Lisa appeared to be very genuine and conveyed the reason for being prepared was so she knew what the report was about. It was my impression the preparation for the meeting was not to ‘get her story straight’, as might be assumed, but rather to mentally prepare for what could lie ahead. Lisa recalled feeling “scared” and terrified” about what was going to happen when the social worker came to tell her about the meeting with child protection services. There seemed to be very little time between being informed of the meeting and it taking place. In this time, Lisa remembered the “horror stories” about the babies of other mothers being taken by child protection services. Although she thought, “there’s got to be more to it, they can’t just take a baby for things like that”, she described feeling very uncertain and “horrified” about the decisions child protection services might make; in this scenario her underlying fear moved closer to reality

After leaving hospital, a number of participants had concerns about the behaviour of ‘friends’, and the possible impact on how child protection services viewed their care of the baby. Lisa described how her housemate had reverted to street drugs after she came home with her baby, and the distress she felt when finding a discarded needle on the floor. Her immediate concern was for the safety of her baby, but she was also “horrified” that child protection services could have come to visit, seen the needle and removed the baby from her care. Lisa described how she needed to move out
because of the need to physically protect her baby and protect herself against being viewed as a bad mother for having him in that environment. She also wanted to know “what was expected” of her in regard to being placed in temporary accommodation; “is having him at a hotel in a pub okay, or is that risk of harm”? Other participants also spoke of the ongoing fear, such as Joanne who described being “wary about slipping up anywhere”. For example, if her child was crying in a shopping centre and Joanne said something, that people might take the wrong way, and make a report.

5.8 It was like I passed a test

One of the more in-depth stories about feelings of judgement, and the women’s experiences of services, emerged from the interviews with Danielle. The context of the story was the first and subsequent home visits provided by a child and family health nurse following her baby’s birth. The first home visit is universally offered to all women in NSW following birth and subsequent visits are arranged according to the needs identified by the nurse and family. However, Danielle described how there didn’t seem to be a choice for her,

*They didn’t say, can she come? They just said, she is coming*

Danielle

Although this might be a subtle difference, and experienced by other women who are receiving treatment with Methadone, the phone call to arrange the home visit conveyed a lack of respect to Danielle, and an indication of surveillance. She had an understanding that the visit would involve some assessment “to make sure I was handling everything OK” but was not perturbed by this, and responded positively to the idea of the visit – “I thought, yeah, no worries, yeah that would be good”. The story of the home visits by the child and family health nurse included a mixture of positive and negative elements. The following extended excerpt from Danielle’s story demonstrates a changing relationship with the nurse during the process of receiving support.

*But then the first day I met her, oh I dreaded her coming for a while. It wasn’t just me either, because after she left I spoke to my husband about it and he got the same as I did. She ended up turning out to be a lovely lady.*
She used to come over every couple of days and just weigh him and just check him out, and just to make sure I was being a proper mum, pretty much. That I knew what I was doing, and I wasn’t stressing out and stuff like that. The way she was saying things though, like asking in a smart or roundabout way...in a nice way, but there was a funny sort of question behind it...it was like she was saying I was a bad mother without directly saying that, you know? Like I could tell she wasn’t sure whether I could do this motherhood thing, but I’m a new mother. There’s a difference between being a new mother and getting advice and help from people, or getting criticism like they don't think that you can do it, and that's how it was with her.

Before she got to know me she was a bit judgemental but after a few visits, things changed and she was a good help, letting me know where to get support and I actually sort of mellowed down a bit with her. She could see that I was pretty comfortable in it and everything was pretty cruisey. In the end, she ended up being lovely and praised me and was like, no, you’re doing a good job, you should be proud. But then she said, “I don’t have to see him anymore, you can keep him”. I’m thinking, what do you mean? You’ll let me keep him; he’s my son! I know it’s her job to make sure the baby’s in the best place, but it sort of pissed me off.

I guess when I look back at it now she was just doing her job, and maybe she’s been in that situation where someone that used to be an alcoholic on methadone or bupe didn't look after their baby, I don't know, but she judged me straight out from the start for that, I know she did. It was like I passed a test. It just gets to you because at the time I was going through a lot - we were homeless and living in the caravan park, then we got a place. So I guess they just wanted to make sure I was okay, and wasn't having that post-natal depression. I know they were just doing their job but she just could've done it a bit differently.

Danielle

This part of Danielle’s story highlights the interplay between the hope of being a good mother and feelings of judgement. Danielle recalls being praised by the nurse; however, the positive phrase, “you’re doing a good job, you should be proud” seemed to be immediately shattered by the remembrance of words spoken at the final
home visit. The relationship changed as one sentence, seemingly spoken in a light-hearted manner, unravels much of what was achieved over the previous weeks. Danielle is later able to reflect that she might have been a bit sensitive to what was said, due to all she has had to cope with in the weeks leading up to the birth and discharge home. However, at the time the words, “you can keep him” seemed to trigger underlying fears that she could lose her baby. Danielle’s incredulous response about permission given to keep “my son” is similar the earlier scenario where she told of how “my son” was “taken” at birth. Even the thought of separation from her baby brought into sharp focus the judgement she felt for being a mother on methadone, needing to “pass a test” to keep her baby.

A concern was also raised by Danielle that the fear of judgement could prevent some mothers receiving methadone treatment from asking for help,

> You might be looked at as a bad mother when you ask for help in comparison to someone who’s never been on drugs... they might think there’s a serious problem behind it with them, but not with you.

Ask for help if you’re not sure, talk to the nurses at the methadone clinic. The CFHN at methadone clinic would probably have more understanding, I definitely won’t see her [CFHN in the community] again...she was pretty much saying and insinuating that I was drinking and that I wasn’t a good mum...she never bluntly said that in her own words, but I was definitely judged, I felt it and I saw it...maybe it was just me, but my husband agreed.

> I try and justify it for her; she had a job to do, but she could have done it differently. I felt uncomfortable in my own home.

Danielle

Part of the “job to do”, from Danielle’s perspective, was for the nurse to assess if there were any child protection concerns. Danielle did not voice any concern regarding this element of the nurse’s role and seemed to accept ‘surveillance’ was required. The relationship was more fragile with the child and family health nurse than with staff at the methadone clinic, who were known and trusted by Danielle, following her contact with them over a period of time.
Other women also mentioned the distress they felt if they were trying to care well for their baby, and they perceived staff were judging them when it was not deserved. Being told they were doing something ‘wrong’, particularly in front of other people, resulted in descriptions of feeling “really small, belittled” and “angry” (Joanne). The anger was related to “actually making an attempt to do the right thing”, but still feeling judged and treated no differently to those who were not making an effort. Joanne was able to see that previously she “was a bit mouthy” when she was angry, but later described how she became more able to “blow it off, because I know I’m not doing anything wrong”. Kristy makes reference to being “snappy” and taking things “personally” when staff seemed to be judgemental and had been “snappy” with her. She was able to reflect that there might be some reason for staff to act in that way, because “maybe they had a bad day”. However, Kristy also realises she is “not that strong to understand it’s their problem”, and was likely to react straight away to anything negative, and become defensive.

5.9 They just wanted me to do what they wanted

As already described, perceptions of the power held by State child protection services was a common element of all the women’s stories. This section provides a more detailed example of the impact of the power held by child protection services, from Nicole’s perspective. Nicole expected child protection services would be involved in issues concerning her child because she was on treatment with methadone, and she conveyed her intention of meeting their requirements to maintain custody of her child. It was not until the baby was around seven months old, and child protection services requested the ‘supervised’ collection of a urine sample for a drug screen, that the relationship changed. Nicole described feeling incredulous she was told to produce a urine sample when she felt she had already proved herself,

*Everyone who had anything to do with me said that I was a really good mum and all that sort of stuff and all my urines from the very start of when I went on the methadone program were all clean. I was like I don’t need to have a supervised urine test. I had to actually go to this place and they’d watch you pee and it’s really demeaning like you know...like turn up with the pram with my baby ...I’m a drop-kick mother [upset]*
she’s saying we can take your baby for that [refusing a urine drug screen]...and stuff like this to me [upset] and I was like what are you talking about, you can’t take my baby, there’s no bloody reason to take my baby. The only way you can take my child is if it’s in her best interest, which this would certainly not be. That’s child abuse to do that to take a baby off her mother for no reason – that’s abusive itself. I was really cranky that she started threatening me that she’d take Sophie if I dared question what she tells me to do [upset]...it simply became like a will thing, like a battle of wills almost [nervous laugh] like they just wanted to make me do what they wanted. They just wanted to win, it became, like it didn’t become about what’s the right thing to do. It just became, No you do what we say, or else.

Nicole

It seemed as if the confidence Nicole had begun to feel as a mother through the encouragement of other workers was shattered by the request for a supervised urine collection. Self judgement, such as describing herself as “a drop-kick mother” contrasted with the description that she was a “really good mum”, as described by others involved in her care. A direct threat to remove Nicole’s baby prompted her to recall other instances where she felt the need to defend and protect her baby against the authority of staff. For example, in the incident with determining the correct dose of morphine for her baby in SCN.

The power and authority of child protection services was portrayed by Nicole as “abusive” as she described how the situation became “a battle of wills” rather than what was reasonable. The situation was resolved by Nicole undertaking the urine collections against her better judgement; it was too hard to fight a more powerful adversary. The conclusion to Nicole’s story was portrayed in a positive light as she revealed that the supportive letters and advocacy of other health professionals involved in her care resulted in the closure of her case with child protection services soon after this incident. I had the impression Nicole felt validated as a good mother.

5.10 I learnt that DoCS are going to be in your life

Other participants also described how their impressions of child protection services changed and varied according to their interactions with individual workers. In all cases, child protection services were initially seen in a negative way, which became
more positive when the participants recognised the support they received, enabled them to keep their children in their care. The stories included both current and past experiences of child protection services, and strong emotions resulted from the recollection of negative experiences. The following extended excerpt from Kristy’s eight year history of involvement with child protection services reveals her ‘journey’ over that time and factors influencing her experiences.

My first impression of DoCS was they are going to take your children; they did it with Ben, after everything that happened with my son that passed away. My first DoCS worker said, “Any children you ever have, I’m going to take off you”. Like basically saying I’m not a mother, bottom line. She was taking her job way against that badge. She was holding that badge up and that almost devastated me for life, thinking that I could never keep my children. Then I had another DoCS worker that said hey, we want to help keep your family together, we don’t like taking children off families unless it’s really necessary.

I’m straight on to thinking the worst case scenario; DoCS are going to take your kids. You’ll run, you’ll freak, you’ll try and protect your child, thinking you’re protecting them and DoCS is trying to protect them. When the child is with you, you want to do anything to keep them. But when your baby is gone, I suppose you are grieving and there is no way you’ll want to do the courses or do what people are asking. It would be hard. It would be like giving birth to a baby, you’ve gone through the whole cycle and then your baby is gone, like having a passed away baby. When they go to DoCS you think, I don’t know where they are, I don’t know who they’re with, all sorts of things go through your mind.

Working with DoCS is much better. I learnt that DoCS are going to be in your life to monitor you and to use them to your advantage by letting them know things, if something happened they could come out and see me; you are getting support. Helping me with this or helping me with that; if you’re going to be in my life you may as well be there for a good reason. I’m going to try and do what I can to work towards keeping them [younger children]. This has been eight years of DoCS, being in the DoCS office where people watch you, and then McDonalds supervised visits with escorts; we’ve come a very long way and I have a relationship with my son. Kristy
The major focus of the beginning of Kristy’s story of her experiences with child protection services was the agency’s power and authority, and suggested abuse of power. The threat to take any of Kristy’s children off her was seen as the worker “taking her job way past that badge” and overstepping her role. More significantly, the impact on Kristy of thinking she had no hope of fulfilling her motherhood role was identified as the “bottom line” or core reason for her distress. The words “it almost devastated me for life, thinking I could never keep my children” reinforced the ongoing impact of the interaction with the child protection services worker. Although I felt sad as I listened to this part of Kristy’s story, the immediate juxtaposition of a positive experience with child protection services, encapsulated in the words “we want to keep families together”, provided a palpable hope not only for Kristy, but also for me as the listener.

Kristy’s story then moved back and forth between the negative and positive aspects of her relationship with child protection services over time and she reflected on this in relation to the impact on her as a mother. Kristy verbalised the effect of having a baby taken by child protection services and compared it to the grief of having “a passed away baby”, resulting in a diminished capacity to work with child protection services and focus on restoration of the child to her care. This part of Kristy’s story ended with her reflection on how she now has a restored relationship with her son (in foster care), and a recognition that she has “come a very long way” to achieve her goal of motherhood. Child protection services are seen as a source of support rather than fear, and Kristy planned to work with them to her “advantage” by working towards retaining the care of her two youngest children, which she describes as a “good reason” for their involvement with her family.

Over time, Lisa’s attitude towards child protection services also changed. The report by SCN resulted in the assignment of a case worker, who Lisa later described as being “lovely, she’s fine”. There was a marked contrast between her fears and the reality of what unfolded following the report. By the time of the first interview, when her baby was eight weeks old, Lisa reflected that other than nurse who put in the report, the “ladies” in Special Care Nursery were “really good” and “pretty fair”. She explained that even if some of them might not seem to approve, “they still give you the benefit of the doubt and treat you how you treat them”. Fairness was linked
to mutual respect. At the second interview, Lisa was comfortable with the involvement of child protection services, and was looking forward to the proposal of follow-up support by the ‘Brighter Futures’, a prevention and early intervention service.

5.11 Summary

In this chapter I have discussed the findings related to the core theme of judgement that has emerged from analysis of the data. Self judgement was reinforced by the judgement of others, including judgement by health professionals and child protection workers. Of ultimate concern to the women was that judgement would result in a report to child protection services and increase the risk of losing the custody of their child. The women described feeling ‘watched’, and judged differently to other women in the perinatal period. The power of child protection services was feared, and the women’s stories included examples of interactions with health professionals and child protection services substantiating their concerns.

The term, ‘Methadone Baby’ encompasses the judgements and guilt associated with having a baby while receiving opioid treatment. The women identified their history of drug taking behaviour had brought them to the notice of child protection services, and they were keen to reassure me that they could stay on the opioid treatment program and care for their baby. It was important child protection services and health professionals saw them as a good mother, as shown by complying with treatment for their drug use, to improve the chances of retaining the care of their child.

The following chapter, Chapter 6 – ‘Being a Good Mother’, presents the findings predominately related to the theme of hope.
CHAPTER SIX

FINDINGS – ‘BEING A GOOD MOTHER’

6.1 Introduction

In this chapter I present the second major theme from analysis of the data – hope. It follows Chapter 4, ‘Nina’s Story’, a collective and chronological account of the women’s stories of their experiences in the perinatal period, and Chapter Five, which focuses on the theme of judgement. ‘Being a Good Mother’ gathers the components of the women’s stories showing optimism, confidence and hope for the future. The women’s experiences of positive and helpful relationships with health professionals and services are found in the sub-themes which include, wanting to be a ‘proper mother’, wanting to breastfeed, and aiming to stay off drugs. Trust, understanding and professional knowledge, were found to be important to the women and the basis of a relationship where the women’s capacity to be a good mother was supported.

In a similar way to Chapter Five, the following findings on ‘being a good mother’ contain some elements describing judgement. The difficulty of separating judgement and hope is evident in some parts of this chapter. In some instances, such as the story of Nicole’s breastfeeding experiences, the separation of the story would diminish the juxtaposition of both elements. The heading and sub-headings of Chapter Six also came from direct quotes from the data.

6.2 Being a proper mother

The women described how pregnancy was the catalyst for change, and how they each took on the responsibility to be a good mother for their unborn child. Caring for a baby provided the opportunity for all the women to have a more acceptable identity than that of a ‘drug-user’. This was more evident in the stories of women who were becoming a mother for the first time, however a subsequent pregnancy also provided
the other women with the opportunity to review their lives. Reflections indicated their awareness of how they had changed over time. For example, Joanne described the change her older son had noticed in her after visiting her at a drug rehabilitation centre, and was able to reflect that previously she hadn’t been the good mother she thought she was.

*She [Mum] said he noticed the changes in me where I'm not angry, I'm not yelling at the kids and swearing my head off anymore. He [eldest son] noticed I barely swore, except little slip ups here and there. Plus, I got up and played with them, whereas before he said, “Mum always had her head in her lap, in between her knees, and drooling. You know, if we woke her up, she'd swear”. I always thought I was the best mother. I think you do, but. You don't realise 'cause the drugs blind you.*

Joanne had some satisfaction she was now more able to be a good mother, even though it was difficult to think about the impact of her earlier drug use on her son. As mentioned in Chapter 5, the women’s stories made it clear they had the intention of doing the best for their baby. The women recognised their drug use put their child at increased risk, and the alternative of opioid treatment was their only option if they were to keep the baby in their care. Central to the women’s stories at this point was their wanting to be a “proper” or “normal” mother despite recognising this was incongruent with opioid treatment in the eyes of themselves and others. Despite this tension, comments such as “I was happy to be pregnant, yeah to have a little miracle” (Danielle), and “I’m really glad she’s here” (Nicole) indicated the significance of becoming a mother although the pregnancies were unplanned.

Evidence of being a ‘proper’ mother, and providing the expected baby care, was present in the stories of all the women. Danielle included in her story how she went to all the classes at the hospital “to learn how to bath him properly, and how to wrap him properly and all those sorts of things”. She described being “in shock I was actually a mother” and was initially concerned that she wouldn’t hear her baby when he cried, or know how to look after him. Danielle wondered if her “natural mothering instinct” would come into play as she felt “I wasn’t very confident as a mother”. She recalled her confidence increased once she had spent more time with her baby, and got to know him, and was able to understand the meaning of his cries.
The women’s stories also provided evidence of the women’s ability to consider their lives from the perspective of their baby, which is generally expected of good mothers. Danielle empathised with her baby when he was teething, “poor baby”, and Lisa described the impact of attending the Methadone Clinic each day with her baby,

*I only walk from home but it just depends how he is, like yeah. Yeah getting both of us ready and making sure he’s all right to come down and he’s not having it – playing up too much between feeds and have to wait between feeds. Though sometimes I really have to either feed him early or bring his bottle with him and feed him on the run and – which couldn’t have been nice for him either – to get down here to do urines and stuff on time.*

Lisa

Emma told of how she struggled with leaving her baby with her mother in order to go to the Methadone Clinic on a very hot day. She weighed up the benefit of keeping her baby out of the heat, and made a choice that was in the baby’s best interest, rather than what she would have preferred to do. The brief separation was difficult for Emma to cope with due to her strong feelings of wanting to be with her baby,

*I wouldn’t leave her with anyone. I left her with my mum the other day because it was so hot. But I ran straight home - got dosed and ran straight home. My mum was like, I thought you’d be heaps longer. Even when I left she’s going, just go, it’s okay. But I thought I was missing something. I couldn’t walk out the door without her. But I just had to - it was too hot.*

Emma

Some of the women’s stories included information regarding accessing health services when their babies required routine immunisation and developmental checks, or if the baby was unwell. Taking the baby to be seen by a GP was mentioned in the stories of Emma, Joanne, Danielle and Kristy. The GP was ‘assessed’ by the women in terms of the level of judgement or non-judgement, but also on the level of care provided for their baby. If the doctor was dismissive of their concerns, they were more likely to look for an alternative GP or medical review, as described by Danielle below.

*Yeah, all the developmental checks are good. He’s perfect and I go to see Dr Brown at the hospital, the paediatrician. He’s excellent. He does a thorough check, he’s good. I’m happy with him....because I seen him once*
through the hospital, like when I had him we organised an appointment and then I just got a referral from my GP and it covers me for a year now. So every three months I go back to him. In the beginning he had reflux and colic. That's what I took him to the doctor's about and he sort of brushed it off, so I seen the paediatrician and then he told me to change his formula and then he was better. Now he hasn't got reflux or colic, so that's good.

Danielle

A number of other examples were offered to consciously, or unconsciously, substantiate the women’s desire to be a good mother. One mother (Joanne), told me how she took her children to the emergency department at the local hospital due to an exacerbation of asthma. Another mother went to a GP, and subsequently to a radiographer for an ultrasound, because her baby had a red and swollen scrotum. On both these occasions, there was a trade-off between the mother’s need to be at the Methadone clinic for their opioid treatment, and the baby’s need for medical attention. The baby’s needs were put first. In addition, Kristy included a large amount of detail regarding the benefit she gained from admission to a tertiary parenting support centre for a residential stay (5-7 days). The impetus for accessing additional support related to ongoing difficulties with her baby’s sleep and settling and acceptance of the referral demonstrated she wanted to be a good mother and care for her baby in the best possible way. In addition, this could have also been influenced by a level of confidence and trust in the nurse organising the referral, and how any barriers to her attendance were minimised.

Kristy’s story included the most information of what it means to be a good mother, based on her experiences with four children over the last eight years. Joanne and Lisa were mothers to more children (five children each and Lisa also the grandmother of two toddlers), however Kristy’s interviews were longer, and her reflections provided more detail. Kristy looked back to her experience of her eldest son going into foster care following the death of her second child, while she was in a relationship characterised by physical and emotional abuse. She reflected that she “wasn’t capable” at the time to care for her child and recalled the words of her solicitor, “there’s plenty of parents, there’s plenty of good people out there who will care for your children”. Kristy went to court to apply for the return of her son to her care, but she was unsuccessful. In retrospect, Kristy was able to say
If I can’t protect them and be a proper mother, I’m better off sending them where they are going to be loved and stuff. That’s a selfless way, if you are off your face and taking pills and doing stuff

Kristy

Good mothers are known to put the needs of their children first, and Kristy told of how she has not applied for custody for her son even though her life has now turned around and she is stable. Kristy explained that she has a “very good and trusting relationship” with her son’s foster mother and it is better for Matthew, particularly because “he’s been with that family for eight years, he’s now ten”. The unique relationship with the foster family has extended to Kristy staying overnight and watching ‘their’ son play football together. A shared motherhood became tolerable as Kristy’s focus moved to her youngest two children.

Now I’m up to the Liam and Adam part, and that is my life and this is where I like to try and stay and keep forward. Instead of like sitting back in the past where I’d be thinking about all the bad things that have happened to me, I shoot forward for the future with the kids... because that’s what they need. Everything is so fun...it’s being a child. Yeah, and I can really just adapt with that and have fun and yeah. We’re like best friends [Kristy and her children].

Kristy

The hope of a better future, a different story to the one in the past, emerged as a significant thread through the data. In the example of Kristy, being able to “shoot forward” away from the past is for the benefit of herself and her children. For her, the outcome of being a good mother was meeting their needs by moving forward, and having time to “have fun” with them. Kristy’s need to experience her ‘lost’ childhood also came to my mind, and I felt sad as she explained about “being a child” and having a “best friend” relationship; something she did not seem to experience when growing up.

As I said before, my mother is a drug addict and my auntie is a drug addict. Rather than giving me food or something it was giving me cones or pot. Mum actually said to me the other day, I gave you all the drugs and everything, you know, I did everything for you. I said, yeah but you just weren’t a mother. Now I have children I know what’s right and wrong for my children and I dread if my son came home and had red eyes or had been
smoking or something like that. I’d want to boot him up the bottom...By
condoning it, Mum thought I wouldn’t go elsewhere and smoke.

Kristy

Kristy recognised that her mother did not provide childhood experiences that
promote healthy development and a secure environment, and the care she describes
was very different to what society would see as appropriate.

6.3 I really wanted to breastfeed

The women appeared to believe that their value as a mother increased if they were
able to breastfeed, ‘a good mother breastfeeds’. All but one participant, who did not
attempt to breastfeed, mentioned breastfeeding in their stories. By the time of the
first interview, four of the five women who commenced breastfeeding in hospital had
discontinued for a variety of reasons. Examples included a recommendation to
change to an anti-reflux formula to manage excessive crying and unsettled infant
behaviour (Danielle), and difficulties with attachment to the breast and the need to
express to build up the milk supply (Lisa).

Lisa briefly mentioned breastfeeding support in her story. She recalled how the
“breastfeeding lady” in the hospital was “helping” and they were “talking” about
how to manage her low supply of breast milk. The midwife was described as being
“really good” and a discussion occurred regarding different strategies to promote the
supply of breast milk including use of medication “that brings your milk in”. Lisa
appeared to be very comfortable with the approach of the midwife and the
subsequent advocacy on her behalf with other staff that “need to understand”.

It seemed important for the women to let me know they had tried to breastfeed to
establish their credibility as a good mother. Kristy was unable to remember why she
discontinued breastfeeding, however, she recalled that it was on the advice of
someone at the hospital and possibly related to managing her baby’s withdrawal.
She regretted not breastfeeding her baby for longer, “I should have breastfed more”
for “the nutrients and the bonding”. Joanne was also disappointed she had
difficulties with breastfeeding, “I was frustrated he wouldn’t take to my breast
properly” and linked this to her baby withdrawing, which reinforced Joanne’s guilt
about not being a good mother.
Nicole and Danielle recalled a similar distressing experience of their baby being given formula in NICU or SCN in the first twenty-four hours after birth, because they were not present to provide a breastfeed. In Danielle’s case, she remembers being advised to sleep through the baby’s second feed as she was exhausted from the labour and birth. On her return to NICU, Danielle was surprised to find “a tube down his nose because he wasn’t feeding properly with the bottle”. Danielle’s response was to make sure she “didn’t miss a feed” after that and was pleased to report the feeding tube was removed that afternoon. Providing the feed for her baby was an important component of being a mother for Danielle and it minimised the separation she felt with being on the postnatal ward while her baby was in NICU. She expressed her feelings about breastfeeding in the following way,

_Breastfeeding was really good. I liked it, but then he got sick with colic and reflux so we had to change him onto AR milk. But I loved it! I fed him for about 10 weeks. When I couldn’t breastfeed him anymore, I was a bit disappointed because I enjoyed doing it. Maybe that closeness I had to him, I don’t know. I’d just stare at him and watch him, how he did it. I was just fascinated how well he went into it. I just enjoyed that moment; that special bond just between us, that we had and no one could take._

_Danielle_

Nicole recalled feeling like an ‘outsider’ in SCN, where the care of her baby seemed to be out of her control. This impacted on Nicole’s early breastfeeding experience, and exacerbated her feelings of not being a good mother,

_Eventually I went down and saw her and the people didn’t really tell me much. They just said oh, we just look after the baby, and you just sort of come and go and stuff like that, and sign this to give her formula and sign this and this and this. I said that I wanted to breastfeed and they said the formula is just if she needs it and stuff like that. Then I left and went backwards and forwards [from the postnatal ward]. Then I was trying to get her on the breast and they didn’t really explain that you can feed her three hourly and if you come down try and make sure you’re here for feeds and a change._

_I was trying to breastfeed Sophie, but because she’d had bottles of formula she was use to the bottle, and I didn’t know when to give her a feed, how to give her a feed, and they said, oh do you want to change her nappy? And I said I don’t_
know how to [embarrassed laugh]. I’d been around babies and stuff but it was all a bit daunting. Like it was my first baby and I didn’t know what to do and they didn’t really ask me.

Looking back on it they didn’t really try and encourage you to be with your baby or anything. It was like they wanted to shoo the parents away almost. Maybe they think that they’re their babies or maybe it’s just easier if the parents aren’t just sort of in the way and asking questions and all that sort of stuff, you know what I mean? So you just go away and you can come visit them when you can, and then pick them up when we discharge them... and I’m like I can’t do that...just when I’ve had a baby [incredulous, upset].

Nicole

Nicole’s distress as she reflected on this experience appeared to be based on the thought of herself and her baby being separated and others taking responsibility for her baby’s care. Language such as “they didn’t really explain”, “didn’t really try and encourage you to be with your baby” and “like they wanted to shoo the parents away” demonstrated the discomfort felt by Nicole regarding her lack of inclusion. The expectation of being with her baby after birth was shattered by the overwhelming feeling that she did not seem to be needed for the care of her baby at a time she wanted to be a good mother. It is in this context that Nicole described the challenges of wanting to breastfeed, and not receiving useful help at that time.

I was trying to breastfeed her and one of the nurses was helping but she was really sort of abrupt and not very patient. So she was getting cranky and sort of grabbing the baby and she grabbed my boob and put it in the baby’s mouth...and the baby was crying and I was crying and it just wasn’t working. The baby would be frustrated because I was having trouble with breastfeeding her, she’d be crying because she’d be hungry, then I’d give her a bottle and she’d chug down the bottle and be content and asleep.

The rest of the time I was in hospital, so many people tried to help me; if anything it became like a nuisance. Like get away from me. It would just always be an ordeal with them grabbing at me and the baby, and the baby crying and me crying and it would just end up being horrible, so whenever anyone came “Oh, you’re breastfeeding”.....great, like here we go.
So I ended up not trying to breastfeed in front of them because every time I would, it would have been an excuse for them to get stuck into me and marking the sheet and everything. I was just really stressed in there so I was just giving her bottles and expressing and putting it in a bottle for her because I didn’t want to bump up the dose of morphine if she didn’t need that much.

Nicole

The help offered by staff seemed to be more of a burden to Nicole than support. She described how her breast and the baby were “grabbed” and attempts to breastfeed became a “horrible” experience. Nicole’s compromise of expressing and feeding her baby breast milk via a bottle reduced her stress, because she no longer required ‘help’ with attaching her baby to the breast. In addition, Nicole’s baby was more settled, and she had greater confidence in the scoring of her baby’s withdrawal symptoms and the subsequent dosage of morphine. This strategy allowed Nicole to maintain her role as a mother, by offering breast milk, and protect her baby from a dose of morphine perceived to be higher than required.

A turning point in Nicole’s story of breastfeeding came as she and her baby were transferred back to a smaller, local hospital. It was in this setting that Nicole came back into contact with a child and family health nurse she had previously met at an opioid treatment clinic. Nicole gave credit to the nurse for her success with breastfeeding, “it was pretty much thanks to Sandra, Sandra was so good I’d recommend her to anyone who’s having trouble breastfeeding”. Nicole was proud to say, “I still breastfeed now, I finally got her on the breast”. Her role as a good mother had been affirmed.

Nicole identified the support with breastfeeding, provided by the child and family health nurse, had its basis in the nurse’s specific breastfeeding knowledge, and the way in which the information was communicated,

Instead of telling, she really knew a lot about breastfeeding and when she came in she said what a good job I was doing, and how good breast milk is for babies, and all that sort of stuff. Then she showed a few different positions that might be good, and she showed me you can lie down and breastfeed. And she showed me this really sort of pretty amazing thing that I’d never seen before, and my mum had never seen it before and she’s had seven kids. She just got the baby in a nappy and me topless, and she lay me back in the bed and put the baby on
the bottom of my stomach. The baby did a little commando crawl up and got on the breast herself and latched on! And for a baby who couldn't ever get on the boob and watch her do that, it was just really amazing! Then I'd sort of put her on the breast and she'd go to the breast.

Nicole

Nicole was very excited when telling me this part of her story, and wanted to know if I knew babies could do this. She found it “really amazing” and wanted to share her new knowledge with others. Hope was given of a different experience of breastfeeding, through the nurse sharing her knowledge in a way that was unobtrusive and effective. The observation that her baby could attach to the breast also gave Nicole hope she could stop expressing. The nurse gave both positive encouragement about breastfeeding, and practical assistance. Useful support was provided by showing “different positions that might be good”; suggestions “instead of telling”.

The aim of feeding directly from the breast was not realised for some months, and Nicole described how tired she became when trying to put the baby to breast and expressing after each feed. She eventually couldn’t get out of bed at night because she was so tired, and recalls she’d “just stick her on the boob in the middle of the night, and she'd whinge and whinge, but I just sort of kept trying, and then it became a night time thing and she’d just go to the breast”. Expressing after day feeds was then gradually also eliminated and at the second interview Nicole was pleased to say,

I was really happy to get her breastfeeding because I really wanted to breastfeed.

Nicole

I am aware other mothers breastfeed despite many challenges, however my respect for Nicole increased as I listened to her story, and observed her baby breastfeeding at seven months of age during the second interview. I felt relieved she received useful support with breastfeeding when it was important to her, and affirmed her as a good mother; something she had striven for since early pregnancy.
6.4 Because I’ve got a baby, I want to stay off drugs

The participants were initially very reluctant to be on an opioid treatment program, but agreed to participate and fulfil the requirements of monitoring, in order to keep their baby in their care. Compliance with a treatment program not only provided the much needed support for transition to a different role, but also provided evidence to staff, child protection services, and general society of the women’s intention to change and be accepted as a good mother.

I’ve never really got off it the proper way before. I was on 100ml and then I jumped off it, like the whole lot. I was sick for about four or five months and I swore I’d never go back on it but I got back on drugs with the wrong boyfriend ...Not now because I’ve got a baby.

Emma

For some, the responsibility of becoming a mother for the first time was the catalyst to follow through with getting off drugs “the proper way”. Emma said she did not want to go back on drugs “because I’ve got a baby”. Motherhood was the chance for a different life, and a different identity. Danielle also told of changes that had already occurred in her life such as getting married to a “different kind of guy than I’d usually go for” - someone who was supportive of her hope to look after her baby and come off the opioid treatment program.

The reality of receiving opioid treatment for the women in the study included the need to travel daily to receive their dose of methadone or buprenorphine. On most occasions, the women described bringing their baby, or baby and toddlers, with them to the clinic. The women either did not have anyone else to care for the baby for this time, or preferred not to leave their baby with anyone. In the second instance, the underlying rationale was that they could be considered to be a bad mother if they left the baby in the care of someone else.

One issue that arose in their stories was the time taken to travel to the clinic and wait for dosing. Joanne estimated that it took “nearly half the day when we were on public transport” as it involved catching a bus, a train and a fifteen minute walk from the station, waiting for her turn for dosing, and then the return journey. Joanne worried about the impact on her children of going to the clinic with her,
I don’t really like them to see the things you see at the clinic and the things you hear, like talk about using drugs and drinking. It’s bad enough having to bring them here, because that’s all they know. They don’t need to be around that.

Joanne

The option of taking her child into the playgroup at the methadone clinic, when it was in operation two days a week, was described as helpful to minimise the child’s exposure to inappropriate talk or behaviour.

The other main impact of daily dosing at the clinic, was the concern for the health of the infants and children, particularly during the summer and winter months. Four of the six women mentioned concerns about the heat or the cold and their child becoming unwell, “I’m dreading winter, I can’t walk around with him. He gets sick.” (Danielle) and “the kids were always sick, dragging them out in the cold all the time” (Joanne). The stories included examples of how sick children then needed to be seen by a doctor which sometimes resulted in the woman missing her treatment.

Other meetings with child protection services or their drug and alcohol case workers, regarding needs such as looking for housing, also impacted on the time available for the women to be at home with their baby. Lisa described how she just wanted to have

a whole day at home with him to enjoy being with him instead of having to rush out and then by the time I get home being so buggered

Lisa

In this respect, the experience of motherhood of the women in the study was noticeably different from my awareness of women not receiving daily opioid treatment. Mothers do not usually have to go out of the house with their baby every day, although some might choose to. Some participants said they were considering a transfer to dosing at a pharmacy so they didn’t have to travel to the clinic each day. However, there was a reluctance to make the change, as they were concerned they would lose the support offered by case management at the clinic. The women felt they might need the continued monitoring to help them fulfil the requirements of child protection services, and not put themselves at risk of ‘losing’ their baby.
6.5 It was good because I could ask questions

The response of staff either reinforced the judgement the women felt for being the mother of a ‘methadone baby’, or provided hope they could be a ‘good’ or ‘proper’ mother, by responding in a way where judgment was felt to be absent or suspended. The development of trust was found in each story and was included in data collected at both interviews. It was also present across all settings and in all interactions with a variety of professionals.

A number of participants made reference to the importance of feeling at ease, “comfortable” (Emma) to ask questions,

It was good because I could ask questions and she reassured me too that I was doing a good job with my son....I could ask questions during the week, or even day to day, because she gave me numbers to ring; it’s a good service

Danielle

I wasn’t scared to ask questions, I would have been worried to ask if they were rude. They answered everything I needed... I would have been out of there [hospital] if they were rude, made any excuse. The nurses showed me stuff, I could ask without feeling worried. They’d just show me.

Emma

I was glad with the services; I could go and ask them

Kristy

As a first time mother, Emma compared the way she was cared for in hospital to her expectations of feeling “worried about going to hospital”. Emma’s experience was much more positive than she expected as the staff were “discreet” with her medication and responsive to her needs. She wondered if others’ experiences were different because they had done something “wrong” or they had gone to another hospital for the birth. The lack of judgement from staff dissipated Emma’s worry and she felt comfortable to ask questions. Emma added that the nurses “showed me stuff” and the care she received did not make her feel “hopeless”. In the second interview, Emma reiterated that she was not “scared to ask” questions and that the staff were “really good to me and to her”. By the nurses responding in this way, the
balance seemed to move away from judgement to hope, resulting in a positive experience for Emma which helped her stay in the hospital environment.

I heard stories and stuff too. That did make me think – because I’m on methadone – that they [hospital staff] would treat me different. But they didn’t at all. I’m grateful for that. I bought them a thank you card and everything. The nurses up there, they were really great. Well especially as we stayed there seven days too – that’s a long time. So I would have been out of there before then if they were rude to me. I just would have made any excuse possible to get out of there.

Emma

6.6 They are understanding

The women linked a lack of judgement, and increased trust, to the way staff understood their perspective, and responded to them as mothers. A number of examples of the care and understanding provided by staff are found in this section.

Joanne was particularly concerned her son might withdraw, and was upset when symptoms indicated he might need treatment with morphine. Other than her eldest son, three previous children required treatment for Neonatal Abstinence Syndrome (NAS) and she was on alert for early signs of withdrawal. Joanne described how her baby was “sneezing all the time, and having little tremors or jerks, not taking to my breast properly, crying all the time and not settling”. A midwife on the post-natal ward spent time with Joanne, and the empathy she was shown assisted her to become calmer. Working together on the score chart provided Joanne with greater confidence in the accuracy of the “really low score” at the time. Joanne’s hope for a different outcome for her fifth child was not realised; however, the support provided by the midwife assisted her to cope with feelings of self-judgement.

Joanne also appreciated the care she had received over an extended period of time from the child and family health nurse at the opioid treatment clinic, and the neonatologist,

...Dr Smith and Diane answered all of them [questions]. I felt that they were always answering me properly and treating me well. They weren’t discriminating against me because baby was going through withdrawals. I
guess because they see it every day and because they aren't that type of people, they are understanding, and they love their job. But see, Diane's known me from when I was really bad. I had all missing teeth and I looked shocking. I looked like 20 years older than what I do. Even she's noticed a big improvement.

Joanne

Joanne appreciated the lack of judgement and that her concerns were taken seriously. She described how the staff answered her “properly” and treated her well, which implied that this was not the case with others who judged her. Joanne considered the development of her relationship with the nurse and doctor was related to their genuineness and understanding of her situation. The language used by Joanne in the statement, “they aren’t that type of people, they are understanding and they love their job” indicated her recognition of the non-judgement and commitment to caring of the staff. This underpinned and supported Joanne’s continued use of the service.

Lisa also told of how staff took her concerns seriously.

Lisa

The acceptance of Lisa’s concerns, about her baby’s unsettled behaviour as a legitimate issue, was an important component in the development of her relationship with staff. Lisa expected they would think she had “Munchausen Syndrome”, which involves creating a story around a health issue to gain attention, and was pleased to have her concerns taken seriously. As a mother worried about her baby, being “listened to and getting the tests done straight away”, was vital to Lisa. She indicated there was no evidence for the staff to believe her, as the baby was quiet
during their review but screaming at home. Lisa’s mothering instinct that something was wrong with her baby was proved to be correct by the test results; she is a credible mother and her baby is now a “dream child” following treatment. The lack of delay in referral for further investigation and the staff’s actions in “pushing all that through” reinforced Lisa’s perceptions of non-judgement and belief in her as a mother.

Danielle identified the support she received was enhanced because the nurses had known her for a period of time and were able to question her responses if they didn’t match other indications of how she was feeling. She explained,

I know these guys here; they’re really great with support and have helped me through a lot. They’ve helped me keep sane and strong, I can open up and tell them my problems. They can tell something’s wrong...you don’t look ok.

Danielle

Danielle compared how she was able to “open up and tell” the staff at the methadone clinic to how she was unable to do this when undergoing rehab treatment. Although this was previously linked by Danielle to the grief of her sister’s death, on this occasion she adds that there needed to be a connection with the health professional, “same as when you’re counselling, you can’t always talk to that person”. The depth of the relationship with the staff at the methadone clinic allowed them to challenge Danielle when she denied there was something wrong, “they can tell”. In this instance, the relationship remained intact, unlike her relationship with the child and family health nurse where the ‘challenge’ was seen, and responded to, as a threat to her identity as a mother.

Kristy’s story also included a section about the depth of the relationship she had with a child and family health nurse after the birth of her previous child. The relationship started when the nurse visited Kristy at home in the days following not only the birth of her third child, but also the suicide death of her partner. She recalls how the nurse and the mental health team were “fantastic”, “non-judgemental”,

...they were even coming and crying with me and saying I was really strong with everything I’d been through...I can remember laughing too and having that uplift
The support and empathy provided at such a difficult time was appreciated by Kristy and she identified similarities in the approach to care by the child and family health nurse and the mental health nurse. In this situation, being treated as a normal mother was even more important, and the positive reinforcement resulted in a strong connection forming between Kristy and the nurse.

She’d ask, “How are you? How are you feeling?”, like the mental health nurses, and then address any concerns that I would have with baby as normal concerns, not because he’s on Morphine or something, but normal – all babies do this and that is why it happens. That made me feel so much better; to just feel normal.

..I saw her for years. I’d go up there [early childhood health clinic] and she’d weigh the baby, check him all over and then I’d sit there and have a break and she normalised it for me. She got it into my head, you’re a mum, it’s no different being on methadone. She dealt more with my problems than baby’s and saying, “You’re a mother, you’re doing a great job, you’re doing this, you’re doing that which is the right thing” was a lot of reassurance. It’s just that reinforcement, it can just be those words that really help you

..I had that support there. I could go up and talk to her and everything. She was more like a counsellor; that really helped when I wondered how I was going to cope with my child. She’s not there anymore unfortunately

Kristy

Contact with the child and family health nurse over an extended period of time, described as “years”, assisted in the relationship development and an absence of fear when accessing support. The reassurance that Kristy was “doing a great job” was helpful because it provided positive reinforcement with evidence of how she was doing “the right thing”; it was more than just an easily given platitude. The words “you’re a mum”, and “you’re a mother”, seemed to verbalise Kristy’s hope to be seen as a good mother, and in the interview I had the impression that Kristy now saw herself in that way. The “help” given was also related to how she could talk to the nurse like a “counsellor” in a way that helped Kristy put her baby’s behaviour and her challenges into perspective, particularly when she wondered how she was “going to cope”. Kristy concludes this part of her story with a comment indicating her
disappointment that she no longer has contact with the nurse, as the nurse has moved away from that clinic. Although not stated, I had the impression that Kristy would have liked to go back to see the same nurse with her most recent baby, and she was almost sad this was not able to happen.

A positive and trusting relationship with staff allowed a freedom for Kristy and other participants to be open about their concerns. Not only were the staff described as being “nice” and “good” but a deeper context and relationship was alluded to by the use of words such as “family” and “sister”.

“I’ve got no family here – they’ve [methadone clinic staff] been really good”

Danielle

“They are good people. Tracey [methadone clinic case manager] is like a sister to me. If I need help I can talk to Tracey; she believes in the ‘keeping families together’ course... when you’ve had a hard time and come, you’re looking for openness.”

Kristy

A two-way relationship with staff characterised by openness and a common goal provided the basis for the women to be less guarded in revealing their problems. In addition, the underlying premise the participants had the capacity to look after and care for their babies, with ‘support’, underpinned their ongoing acceptance of care. The focus of staff on working towards the mothers keeping children in their care, “keeping families together” in a planned way reduced the anxiety of the women that their baby could be removed. Perceptions of judgement were diminished and the hope of being a good mother started to move towards becoming a reality.

6.7 They’re nice, and professional about their job

The common thread of hope was interwoven through the stories of the women in both subtle and more overt ways. Acceptance as a “normal person”, a “normal parent” provided hope during interactions with staff, or even not being seen as “hopeless” as described below,

“They wouldn’t make me feel like I was hopeless or anything. So it was just pretty good.”
Nicer nurses chat like normal, like to all the parents. They’re nice, and professional about their job. They don’t feel they need to teach people a lesson; it’s good not to be judged by your situation. It helps if they treat you like you expect to be treated... normal, not insulting.

Nicole

Treat people the way they [staff] treated me, with a bit of respect. Just to not look down on anyone and treat them like they’re a normal person and not like they’re on methadone....the thing is too they’ve got to understand is that being on methadone, you’re on a treatment plan, you’re trying to get help, you’re not doing it just because you want to be on drugs. We still feel broken anyway we’re not totally healed from it.

Emma

Being treated with equality and respect was seen by the participants as an important part of developing a positive relationship with staff. In comparison, feeling judged and treated differently because they were receiving opioid treatment was “insulting” (Nicole), and indicated staff might “look down on” them (Emma). Talking with staff became a more relaxed “chat” for Nicole when there was less of a power distinction. This was then immediately compared to the judgement that would be felt if staff stepped outside their professional role to “teach people a lesson”.

The tenuous balance between hope and judgement was ever present, however it seemed to lean towards hope if staff had an understanding that the women were trying to move out of their “situation” (Nicole) and were “trying to get help” (Emma). Recognition that the process of becoming ‘normal’ is difficult and ongoing, as indicated by the language used by Emma, “we are still broken...we’re not totally healed”, which seemed to be a plea for understanding and empathy.

In general, trust to ask questions or disclose concerns developed over a period of time as the participant’s relationship with the staff and service increased. The main exception in the data was in Kristy’s story of her interaction with the hospital social worker. In this instance, Kristy identified the development of trust occurred at her first meeting with the social worker due to her non-judgement, empathy and responsiveness. This was sufficient for Kristy to “pour out everything”. It seemed
the personal qualities and skills of the social worker and the timing of Kristy’s need to talk to someone provided the opportunity for effective help to be given with her problem.

In the second interview with Kristy, I asked a question regarding the psychosocial questions which are a component of antenatal booking-in, and the maternal and family assessment at the first home visit. Kristy initially thought she would not be open in her responses to the questions as it was the first occasion she had met the staff member, and trust had not developed. However, when providing this response she immediately reflected this was not her experience with the social worker,

*If there was something going on, I don’t think I would actually indulge to tell them because I’ve never met this person before. Yes, I would feel like that rather than if it was someone like Diane [CFHN at methadone clinic] or someone I know and like I can trust...No, but the social worker, I was good with her, actually she was fantastic, so that’s where I went all out and everything like that because of the help; the help and the compassion I felt from her, that was what it was*  

Kristy

Kristy identified trust was developed early because of “the help and compassion I felt” even though she instinctively didn’t think she would “indulge” to tell a staff member of any concerns if she had not met them before. Kristy later also reflected she was worried about “telling the truth” to get help because of her underlying concern of ‘losing’ her children. However she added, “it was the best thing I ever did, I’m glad I did because they help you”.

Kristy’s story was extensive and she expressed her appreciation of staff supporting her at different times in the perinatal period,

*It was fantastic that midwife there was just very non-judgemental. Whatever question I asked her was handled in the right way. I actually wanted to nominate that midwife, just her care....Are you OK today?...I’ll get you your medicine, or this and that, where everyone else that was on was, you wait, or I will get it to you soon. She was excellent.*

*She looked after me as a mother and being on methadone as well; so that was fantastic, I enjoyed it. That was great, because otherwise you want to*
run out of hospital. When the littlest thing happens you want to pick the baby up and take them out of hospital....some people are prejudiced – just little things

Kristy

Kristy’s thought to nominate the midwife for her care was based on her non-judgemental approach, but also her ability to pre-empt her needs “as a mother and being on methadone as well”. Kristy’s identity as a mother was separated from her identity as a person requiring opioid treatment. Being “looked after as a mother” was of primary importance to Kristy and she wanted to emphasise its significance to me. In comparison, “little things” or perceived judgemental responses by staff were thought to be indicative of prejudice, and had a negative impact on remaining in hospital.

The importance of helpful advice and a positive experience of services was also evident in Kristy’s story where she described her strong relationship with a child and family health nurse with her previous baby. In that context, the advice given regarding how to cope with a very unsettled and crying baby was remembered as being very helpful and applied to her current settling difficulties. If the relationship had not been established, there would be less opportunity to provide the information to Kristy.

“There’s been a few stages when I was at home and baby wouldn’t sleep, wouldn’t do anything, and I am like I have to get to Karitane or somewhere like that and I’d forgotten where all my numbers are. I wanted to ring up and just say oh look he won’t stop.

Like with Liam [previous child], Mary told me, she said you put him down, put him in bed and if you are stressed, he’s stressed, walk out of the house. I am like – I can’t leave the house. She is like no, you go where you can’t hear him, make sure he is safe, he is in a cot and go out until you can’t hear him anymore and you calm down... Then go back in there. You know, it’s no good sitting there and going “just stop crying, what you are doing’, you know, like that’s no good to him, doing that”.

The strategy of leaving the baby safely in the cot and the mother taking a few minutes ‘time-out’ to calm down away from the baby is commonly suggested to mothers who are becoming stressed with their baby’s constant crying. Prevention of
“shaken baby syndrome”, which can cause brain damage to infants when parents are extremely frustrated and exhausted by excessive infant crying, is a key health promotion message provided by child and family health nurses. The ongoing usefulness of the advice provided by the nurse was demonstrated by Kristy’s recollection of the message, and recognition that there were services such as Karitane to phone for support.

6.8 I really looked forward to her next visit

It was important for the participants to have a physical check of the baby and the opportunity to discuss sleep and settling, feeding and any other concerns with a child and family health nurse. These aspects of the universal health home visit reinforced their mothering role and the women seemed to enjoy telling about me about this part of their story. Information regarding the general care of their infants was described as being helpful by all the participants who received a home visit by a child and family health nurse. Nicole provided the most data regarding her experience of visits by the child and family health nurse as she describes in the following excerpt,

Robyn's really good, I really like Robyn too. She's great, she knows lots about everything I have to ask and you know, the house had been sort of a bit of a mess and stuff like that, and she wouldn't mind. It bothered me that the house was a mess, but it didn't bother her [laugh]. I just sort of had all baby stuff piled up in rooms and in the lounge room it had become a little sort of oasis, because Sophie slept with me. I put the mattress on the ground, so that if she rolled out she wouldn't hurt herself. I had my TV out there ...sort of had the change table with the wheels and has the bath underneath and I had all the baby stuff in that and like I had my own little system in the lounge room and the kitchen and the rest of the rooms were just storing all my stuff.

Yeah, it was exciting, you know. Getting her weighed and seeing how much she weighs. You know with most social workers and stuff you don't really look forward to the next visit, but I'd really look forward to the next visit. To see how much Sophie had grown, and even to have a chat about the baby and all that sort of stuff and just because Robyn was nice and I enjoyed her company and stuff and yeah, I just looked forward to her coming. Yeah, so
that was really good. She was telling me stuff about like bathing the baby and you know if I had a problem like Sophie had thrush in her mouth, I could get advice, you know just advice on nappy rash and just all those sorts of things.

It makes a difference, it makes a big difference if the person’s nice [nervous laugh] and if they know what they’re talking about as well; yeah, both those things. If they know, if they actually know what they’re talking about, because sometimes people tell you all different things ... yeah they [Robyn and Sandra] really knew a lot of helpful stuff, so that was good.

Nicole

Nicole commenced this part of her story by conveying how non-judgemental the child and family health nurse was when coming into her home. Nicole was initially concerned about the house being “a bit of a mess” however it did not appear to be of concern to the nurse, and the non-judgement aided the establishment of a positive relationship with the nurse. As Nicole explained about the “mess” she also described how she had set up the house to care for her baby; “a little sort of oasis” where she could care for her baby. I had the impression that in doing so, Nicole subconsciously reinforced to herself and to me that she was thinking about her baby and fulfilling the ‘good mother’ role. Nicole was quite animated as she described how she found it “exciting” to have her baby weighed and to see how much she had grown. The pleasure she exuded when remembering this affirmation of her mothering ability was almost palpable; all mothers crave reassurance that their baby is growing well and Nicole was no different.

It was clear that Nicole felt at ease with the child and family health nurse to ask questions and seek advice in the care of her baby. Nicole went as far as to say she “looked forward” to the nurse coming to her home and other positive language such as “nice” and “enjoyed her company” indicated that Nicole had a relaxed and comfortable relationship with the nurse. Nicole also included her confidence in Robyn’s knowledge and described advice as “helpful” when both these factors were present, “it makes a big difference when a person is nice and if they know what they are talking about as well”. Asking questions and having a conversation with a nurse provided the opportunity for Nicole and other participants (Kristy, Danielle, Joanne and Emma) to receive positive feedback and reassurance they were good mothers. I
recall feeling almost relieved that there was a ‘happy ending’ for Nicole with breastfeeding and increased parenting confidence. After a long story of despair and judgement, I wanted her to have a positive and helpful experience of services, so that she could enjoy her baby and being a mother.

6.9 I’m going to change this and make it

Resilience was an important facet of hope for the participants. In particular, Kristy was able to look back over the previous eight years and consider not only the difficulties, but also her ability to overcome adversity with support. She identified that each day could be a challenge, but she now had confidence to ask for help when it was needed from services and her family. Hope of a better life for her children was fundamental to Kristy’s attempts to break the “vicious cycle” of drug use. The following extended part of Kristy’s story has been included because it encapsulates what she has learnt not only over the last eight years but also provides insight into why Kristy is so determined to be a good mother and create a different future for her children,

_The doctor asked me yesterday, he said you’ve been smoking since you were fourteen don't you want to give up? - I'm like it's the emphysema in my lungs, I'm on cigarettes why would I want another cone. I want to live to forty-five, fifty at least; my kids need to have that twenty years or something. You live recklessly- it's poisonous. A week ago had you have spoken to me, I would have been that different person, sorry two or three weeks ago, before Tresillian I would just be striving for what I could. I would have been so tired, just fed up, had no time to recognise my children - how happy they were and everything, because mum's got this stress and that is just a disaster. Without my Nan and Pop, without the support that I've had I may have ended up in the nut house having a break for my sanity._

_I suppose to me, I have to sort of take that [DoCS involvement] because I have to work with that if I want to have my children. That's my biggest goal is to keep the children and not only to keep them but to do the right thing by them. It's no good me having them if I am abusing them or I am going out doing stuff. I'm not giving them the life that they could have. It's a vicious cycle that keeps going around and around unless you put your foot into it_
and go ‘no more’. I’m not, you know, I’m going to change this and make it because you pass it down to them. My mum passed it down to me. I really do believe that.

If they [staff] see that people are down and out, let them know that there is that hope; it isn’t that there is no hope out there. It is hard being a mum, I have been there - I’ve had all these things dealing with me, but I’m still capable today of dressing them, feeding them, keeping them clean. I love to make sure their skin’s nice, their ears are clean, their nails are done. It gives me pride to look at my children and radiate from how looked after and cared they are….I’m still pushing for the point where I can get back to work, it’s being society acceptable and keeping myself busy and organised. The goals are there to aim for the future; it’s important for them to look up to me.

I had a lot to deal with, now I’m thinking, I’m going back to my childhood. I have had a lot to deal with. I was a very unhappy child, looking in the mirror; my mum’s not coming. I was seeing a psychologist by the time I was six-years-old. I did have all those things but being able to see the sun rise. Sometimes you can’t and you keep going and I know I have that strength, that it's a whole community. It's not just me - I have to give myself credit for things I do because sometimes I’m not doing that - that confidence, and that support around.

If I can’t then I’m going to fall back. I’m going fall back here and I’m going to fall back there, but they’re [staff] going make me okay for that day and I’m going to get pushed up. My friends around are supportive - say hey we’re here if you need to talk. Everything helps so that’s where I am.

Kristy

Over time, Kristy’s confidence as a mother increased with the support of services and she strongly conveyed to me her goals and hope for a future with her children. I was initially surprised by her aim to live to “forty-five, fifty at least” to care for her children as it seemed a short life expectancy and my expectations were challenged due to my own age. However, from Kristy’s perspective and age of twenty-seven years, her aim was another life-time away. Her overall goal of “keeping the children and not only keep them, but do the right thing by them” was contrasted to how her mother did not care for her adequately. Kristy wants to break “the vicious cycle” to
try and prevent her children being affected by drug use and its associated problems. Her reflection on her childhood, particularly the picture of Kristy as a young, “very unhappy” child looking in the mirror and waiting for her mother to return, was very powerful. Kristy quietly told me this part of the story and I caught a further glimpse of her sadness as she said, “My mum’s not coming” and described her need for treatment by a psychologist at six years of age.

As a result, Kristy wanted to be a good mother and importantly to be there to guide and help her children in a positive way. As with any other mother, she takes “pride” in how well her children are cared for; an indication that she is “capable”. Kristy also linked evidence of the care of her children to her own very positive reinforcement that she is a good mother, when she stated, “It gives me pride to look at my children and radiate from how looked after and cared they are”. There was a stark contrast between this picture of warmth and happiness and the way Kristy described her own experience with her mother.

Hope for the future continued to be central to Kristy’s capacity to move forward despite “all these things dealing with me”, and she wanted staff to know they should provide hope to “people that are down and out” and have also gone through difficult experiences. Being able to “see the sun rise” and have hope was identified as the basis of her resilience. Kristy appeared to be aware that life would continue to have its challenges, and that she would “fall back here and “fall back there”. However, she described how support from staff to “feel OK for the day” would help her to move forward and “get pushed up”. In addition, support from family and friends and Kristy’s recognition of her own “strength” was seen as the context for a “whole community approach” to moving forward as a good mother.

Although this section has focused on the story of Kristy, the stories of the other women in the study also included elements of the hope of a better future for themselves, and their children. Significantly, the women were able to gain a better understanding of the impact of domestic violence, and started to make choices for a safer environment for their children. The women themselves were able to see changes over time, and wanted to be a ‘good mother’ for their child, and for their own self-respect. The determination to ‘succeed’ as a good mother was strengthened
by the support gained from accessing services, as well as a level of support from close family members.

6.10 Summary

Support from non-judgemental, empathic and knowledgeable staff was important to all the women, and provided hope. The women were more likely to access services where they felt accepted as a mother, and where advocacy was provided to support them through a range of problems or difficulties. Trust was developed through staff listening and demonstrating an understanding of the perspective of the women, and by working together to manage issues or problems that arose. This partnership approach reduced feelings of judgment and the fear that child protection services would intervene. The data included evidence of the determination of women to make changes to their lives for the benefit of their children with the support of services. Hope of being a good mother incorporated a sense of optimism that the health and life of their child would be better than their own.

In the following chapter I discuss the study findings in relation to the literature, and consider the four key areas of identity, surveillance, resilience, and the hope of a better future.
CHAPTER SEVEN

DISCUSSION

7.1 Introduction

The study has offered women receiving opioid treatment an opportunity to share their stories about interactions with services during pregnancy and the early childhood period. It has been both a privilege and challenge for me as a child and family health nurse to hear from these women the detail of their stories, as often midwives and child and family health nurses are not privy to the extent or complexity of their experiences. Reluctance to engage with anyone who might be considered an authority figure can also impact on these women’s decision to participate in research. The stories of six women, told to me over two interviews, are therefore an important contribution to understanding their individual and collective perspectives.

The following discussion examines four key areas from the study findings. Consideration of these areas provides a deeper understanding of factors acting as barriers, or enabling the use of health services, by women with complex needs. The chapter begins with the concept of ‘identity’, particularly the women’s desire to change their identity from the judgement and stigma of being a drug-user, to that of a ‘good mother’. Secondly, surveillance is discussed, including the impact of the mandatory reporting role of health professionals on the development of a trusting relationship between the woman and the nurse. The third section of the chapter considers resilience, and how factors such as hope, can assist women to achieve their goal of caring for their children. The chapter concludes with consideration of factors influencing a better future for the women and their children.
### 7.2 Identity

The women in the study wanted to change their identity so that first and foremost they were seen as mothers. Shifting their identity, from drug users to ‘good mothers, was central to each story and to the findings of the study. The desire to be a ‘normal’ mother, with “an unremarkable parental identity” (Huxley & Foulger, 2008 p.13) is common to other studies involving women accessing treatment for drug use. Although I anticipated that judgement about them as mothers would be a factor influencing the participants’ engagement with services, the strength of the findings associated with changing identity were not expected. Judgement, stigma, discrimination, and being viewed as ‘deviants’, contributed to an identity that did not match the women’s hope for the future with their children.

Fear of judgement by others and self-judgement, were found to negatively influence access, and engagement with health and other services in the perinatal period. To the women, having an identity as someone receiving treatment for drug addiction, and the mother of a ‘methadone baby’, equated to being a ‘bad mother’. These women’s self-assessment underpinned interactions and relationships with family, friends, and health professionals and they expected to be judged. The concept of judgement is now explored to get a better understanding of the impact on the women.

Judgement and the related concept of stigma and discrimination has been explored by sociologists and anthropologists (Goffman, 1963). Stigma is described by Goffman as, “the disgrace itself rather than the bodily evidence of it...an attribute that is deeply discrediting” (Goffman, 1963 p.2). Goffman’s foundational work includes “drug addicts” in a list of social deviants during his discussion regarding the issue of stigma, and its impact on personal and social identity (1963 p.143). Judgement and stigma are not new to society; as stated by Goffman, the term ‘stigma’ originated from the Greeks,

> “to refer to bodily signs used to expose something unusual or bad about the moral status of the signifier...and advertised that the bearer was a slave, a criminal or a traitor – a blemished person, ritually polluted to be avoided, especially in public places”

(Goffman, 1963 p.1)
In the study, participants such as Kristy used similar terms as she reflected on the personal and common experience of stigma for mothers receiving opioid treatment; “there’s a sign on my face... we’re seen as a whole different race”.

A recent report for the UK Drug Policy Commission (Lloyd, 2010), on the stigma of substance abuse, highlighted the issue of perceived responsibility and blame. Many in our society consider that problem substance users only have themselves to blame for their addiction by choosing to take illegal drugs in the first place. Drug users are often seen as criminals and deserving of negative and discriminatory treatment. Furthermore, increased blame and stereotyping has become attached to those of lower socio-economic status, in comparison to problem substance users who are not financially disadvantaged. For example, use of cocaine and ‘designer drugs’ by young ‘upwardly mobile’ males (Banwell & Bammer, 2006; Huxley & Foulger, 2008). Until recently, addiction has predominantly been regarded as a disease, a condition requiring treatment to protect society against the risk of ‘contamination’ (Ettorre, 2004). For some, a level of social control is required to manage risks associated with drug users (Peterson & Bunton, 1997 p.215). The historical solution to the problem of substance misuse has been to support abstinence, and treat addiction. In comparison, the current post-modern approach of ‘harm reduction’, allows for a broader understanding of the challenges and social inequalities facing individuals, and provides greater opportunities for holistic care and response to a complex problem (Ettorre, 2004).

Despite a shift in approach to the problem, the literature supports the view that women are judged differently to men in regard to substance misuse. Women identified as drug-users have been described as being “doubly deviant” due to the expectation that they will be “sexually promiscuous” to support their drug use, which “conflicts with their place in society to bear and raise children” (Copeland, 1997 p.186). The reproductive function of women draws attention to their moral or medical ‘suitability’ to reproduce, with the bodies of pregnant drug users described as “lethal foetal containers” (Ettorre, 2004 p.331). Jackson and Mannix (2004) also use a feminist framework, to examine the way in which the actions and behaviour of women who are mothers, are “subject to scrutiny in ways that men as fathers are not” (p.150 ).
The identity of a woman as a mother is questioned even more if she is young and homeless, as found in a study undertaken in Melbourne, Australia in 2006. The young mothers (aged between 17 and 26 years) believed:

... others viewed them as ‘sluts’ and ‘bad mothers’. Societal and parental disapproval had practical consequences such as discrimination and lack of support, and also contributed towards stress in relation to negative self perception

(Keys, 2007 p.15)

A number of the young mothers who participated in the ‘Becoming a Mother’ project, previously had “a chaotic existence often involving substance abuse” (Keys, 2007 p.6) and some were involved in child protection services.

Social identity provides the context for the development of personal identity, and individuals or groups feel a measure of acceptance or rejection by society. All the women in this study either directly or indirectly, attributed their social identity, and the resultant judgement, to being viewed first as a “junkie”. However, the women wanted to be seen as ‘normal mothers’, in line with Goffman’s consideration of this issue,

The stigmatised individual tends to hold the same beliefs about identity that we do; this is a pivotal fact. His deepest feelings about what he is may be his sense of being a “normal person”, a human being like anyone else, a person therefore, who deserves a fair chance and a fair break

(Goffman, 1963 p.7)

In the study, this was clearly echoed by one of the study participants, Nicole when she stated, “don’t take any notice of me, like I don’t want the best for my child, how could I possibly love her on methadone?” Nicole’s distress at arriving at this assessment of society’s view of her as a mother seemed to indicate this was the crux of the matter for her. The difficulty of removing the ‘junkie’ or ‘drug-user’ label is acknowledged by a number of authors (Lloyd, 2010; Peckover, 2002; Radcliffe, 2011). Virokannas (2011), found the main challenge for women with an identity as a drug-user was the difficult struggle “to illustrate that they did love their children even if their previous actions might have indicated otherwise” (p.341).
Current participation in an opioid treatment program challenged the women’s view of their identity as a ‘normal person’, and supported the negative perception they were a ‘bad mother’. When perceptions are reinforced by a lack of respect and regard from others in society, negative roles become the way in which the person expects to function; the individual “echoes this denial by finding that some of his own attributes warrant it” (Goffman, 1963 p.8). In the study, feelings of self judgement were at their highest if the baby showed symptoms of withdrawal after birth and required admission to a special care or neonatal intensive care unit for treatment with morphine. The women reported feeling both responsible, and distressed by this. For example, Joanne described the guilt “we feel” if the baby required treatment with morphine after birth, “having to pour morphine down my son’s throat. I can never forgive myself”.

The study participants individually told of how they were in the process of moving away from their previous identity as drug users, towards a new identity as ‘good’ or ‘normal’ mothers. At times the collective pronoun, ‘we’ was used, or the women spoke in the third person, as they reflected on their lives and experiences with services; their individual story was part of a larger story. Throughout their stories the women emphasised their intention for a positive change in their lives. This is in line with the work of Goffman and authors such as Radcliffe (2011), who explored the concept of a ‘moral career’; changing your identity to one that is more acceptable to society (Radcliffe, 2011). A significant amount of ‘work’ is required for women to move from being a drug-user to a becoming a ‘good mother’. For example, commitment to daily opioid treatment, remaining ‘clean’, attending appointments with case managers, prescribers and child protection services, as well as demonstrating that their child’s physical and emotional needs are met (Radcliffe, 2009). The provision of tangible examples of how the women demonstrated their mothering capacity was a common thread to the stories of each woman in the study. The stories shared by the women incorporated “narratives of change”, as described by Radcliffe (2011 p.986) with the overall goal of ‘keeping’ their children, and providing a better childhood and future than the one experienced by the women themselves.

Further discussion regarding transformation to the identity of a good mother can be found in the section on resilience, as factors supporting change are considered.
7.3 Surveillance

Issues and challenges related to identity influenced the response of the women in the study to surveillance by health and child protection services. Consideration of the impact of surveillance, and women’s perceptions of professionals with statutory responsibilities, provides a greater understanding of how women with identified vulnerabilities engage with services. Historically, public health surveillance was instituted by governments to address high levels of infant mortality and morbidity in the early 20th century (Roche et al., 2005). At this time, in the United Kingdom, the nurse was promoted as the ‘mother’s friend’ (Davies, 1988). Health surveillance is maintained by governments today, as they continue to strive to promote health through prevention and early intervention strategies, and provide support to those most at risk (Commonwealth of Australia, 2009; NSW Department of Health, 2009b).

Public health surveillance is a routine component of child and family health practice, which includes regular review of the physical, social and emotional health and development of children, the prevention of disease, for example by immunisation, and referral for intervention where necessary. This public health approach to health surveillance has been considered to be a benign and caring activity, with shared power to meet common health goals. Crisp and Lister (2004), found nurses perceived their role as one of providing support and advice to vulnerable families. However, for women in this and other studies, even engagement in antenatal care and routine child health surveillance posed a ‘risk’ to their identity as mothers. The concept of ‘surveillance’, therefore requires further consideration in view of perceptions of some women that ‘support’ provided by health services may be negative, rather than positive and useful (Jack, DiCenso, & Lohfeld, 2005; Wilson, 2001).

Complicating a positive appreciation of public health surveillance is the view that any surveillance is an expression of power. The work of Foucault, a French theorist and historian, provides a framework for considering ‘power-relations’, and disciplinary power which impact on the development of a positive relationship between clients and health professionals. Rather than limiting power to overt
instances of oppression from authoritative agencies such as governments, Foucault suggested that power also operated at “a micro, local, and covert level, through sets of specific practices” (Petersen & Bunton, 1997 p.xi). The ‘normative’ practices of medical institutions to provide solutions to people’s problems can be seen as a coercive and disguised expression of power, with a level of “moral authority” (Peterson & Bunton, 1997 p. xiv).

A growing number of authors have considered the work of Foucault and the inherent nature of ‘disciplinary power’ within the role of health care providers (Jack et al., 2005; Marcellus, 2005; Peckover, 2002; Wilson, 2001). Even routine health surveillance can be viewed as ‘watchful waiting’, with implications of ‘power-over’ and subtle coercion (Marcellus, 2005). A more focused gaze on the family, to detect signs of abuse, can lead to the uncomfortable identification of nurses as ‘health police’ (Crisp & Lister, 2004; Marcellus, 2005). As a result, a tension can then exist between providing support to vulnerable families and a ‘policing’ role, where the home environment and parenting practices are observed through a “disciplinary lens” (Roche et al., 2005). Interactions seeking to actively detect any signs of abuse is challenging for nurses, and increases feelings of wariness, ambivalence (Marcellus, 2005), vulnerability and powerlessness (Jack et al., 2005) in those most in need of support.

Surveillance, resulting in the loss of custody of a child was the greatest fear of the women in the study, replicating other findings and a reason why women may delay seeking treatment (Huxley & Foulger, 2008; Phillips et al., 2007). Radcliffe (2009) described the removal of a child by child protection services as the “ultimate sanction” (p.19) against the woman as a mother, a source of both distress and shame. The removal of a child from a mother’s care implies she has not complied with those acting in the best interest of the child, and demonstrates to all that the woman’s status as a mother has been revoked; a ‘black mark’ is now on her ‘report card’. Two of the six women in the study had experienced this situation and the other women were aware that at times this could be the outcome of reports to child protection services.

The study findings also indicate that the power and authority held by health professionals could be misused. Kristy’s recollection of the threat of a worker to take away any children Kristy ever had, not just the removal of her current child, was
described in terms of “taking her job way against that badge”. This was viewed by Kristy as an overstepping of the power invested in the worker, with long-term implications which Kristy later reflected as “almost devastated me for life”. Another participant, Nicole perceived the visit of child protection workers to her home when her baby was seven months old, as an extreme level of surveillance. The power differential was felt very strongly, and relayed by Nicole in the phrase, “you do what we say or else”. Nicole identified that if the agency responsible for protecting her child from harm actually removed her child “without good reason”, they would be guilty of “child abuse” rather than her; an uneasy thought.

Knowledge of the mandatory requirement to report concerns regarding risk of harm to a child identified through surveillance, has been shown to influence the development of trust and acceptance of support involving families with identified vulnerabilities (Callaghan, Crimmins, & Schweitzer, 2011; Department of Community Services, 2005; Jack et al., 2005; Marcellus, 2005). These findings were replicated in the stories of women in the study. The women appeared to have limited awareness of the conditions that could result in their child being removed from their care, and their stories reflected an ongoing uncertainty about what might happen. Phillips et al. (2007) found that women disclosing substance use in pregnancy were not clear if this would later necessitate the removal of their child. It seems the unpredictable nature of the ‘threat’ of being reported to child protection services, can place women in a situation where they are ‘walking on egg-shells’; a situation similar to women experiencing power inequalities in relationships affected by domestic violence.

The times of greatest opportunity for surveillance of the women was during hospital admission for the birth, and a visit to the home by a child and family health nurse as part of universal service provision. Concerns for the wellbeing of the infant were raised in a study of nurses caring for the newborns of drug dependent parents. The neonatal nurses were uneasy about the discharge of babies into potentially unsafe home environments (Fraser, Barnes, Biggs, & Kain, 2007), particularly if there was limited collaboration with social workers and child protection workers, and a lack of awareness of plans for ongoing support. The women’s stories also provided a clear illustration where ‘surveillance’ by nurses resulted in a notification to child protection services. This occurred in the hospital setting by a neonatal nurse, who
was perceived to be ‘not knowledgeable enough’ by the mother. Although the mother indicated her distress at being reported for being unsafe in caring for her baby, she was later accepting of supports put in place in collaboration with a range of professionals involved in her care, as they aimed to assist her in maintaining the custody of her baby.

Surveillance in the hospital setting was concerning for the study participants as evidenced by references to being watched and feeling judged, however surveillance in the home environment can result in a greater level of anxiety in families who feel health and child protection services are a threat to family integrity. Jack et al (2005) explored the experiences and perceptions of twenty mothers with children identified to be at risk of developmental delay as they engaged with nurses and ‘family visitors’ entering their homes. The mothers reported feeling vulnerable and powerless as they allowed service providers into their personal space, described by Liaschenko (1994) as a “creeping extension” of surveillance previously confined to the public domain (p.22). Jack et al. (2005) described the first phase in a process to limit the impact of surveillance was ‘overcoming fear’, an indication that a power differential does exist and needs to be moderated. Once this has occurred, the next stages of ‘building trust’ and ‘seeking mutuality’ can be commenced and developed. The process was fluid and influenced by maternal characteristics and perceptions of the role of the nurse, requiring ongoing negotiation at each home visit. In the study, this was evident in the story of Danielle where the relationship with the nurse was tentative, and fluctuated according to her perceptions of being judged as a ‘good mother’.

A number of authors consider that subtleties of practice associated with surveillance can be as concerning as a more overt and direct approach to monitoring families. Wilson (2001) discusses the idea of “gentle surveillance” where mothers continue to engage with services due to a non-threatening approach by nurses. The idea that the woman could be ‘hooked’ firstly by “wanting to be a wonderful parent” and secondly by wanting “a wonderful relationship with the nurse” (Wilson, 2001 p.298) brings into question ethical principles underpinning nursing practice, as suggested by Marcellus (2005). In a similar way, Peckover (2002) considers the establishment of ‘pastoral power’, where personal thoughts might inadvertently be exposed through confessional techniques. These ideas fit with Foucault’s concept of disciplinary power, and challenge nurses’ perceptions of their supportive role. An imbalance of
power often results in resistance (Wilson, 2001), which may be shown through submission (Marcellus, 2005), or avoidance (Peckover, 2002). The idea of an equal partnership is challenged if women chose not to be open and honest with the nurse, and if the only “satisfactory solution is to stop using the service” (Wilson, 2001 p.299).

However, women have indicated that there are some essential components of relationship development which have the capacity to mitigate the power invested in the nurse. Phillips et al. (2007) found that an open, non-judgemental and supportive ‘practice style’ of midwives was a motivating factor for the disclosure of substance abuse. Health professionals who showed empathy, listened, and advocated for the women in the study were remembered. These, and other qualities and skills of ‘helpers’, as described in the Family Partnership Model framework (Davis & Day, 2010), were embedded in positive descriptions of exemplary clinicians in the study. A reduction in feelings of powerlessness resulted from this positive practice style. On the other hand, professionals with stereotypical and judgemental perceptions, who provide directive or paternalistic advice (Jack et al., 2005; Wilson, 2001) reinforce the women’s inadequacies and heightened their negative perception of surveillance.

Although women receiving opioid treatment may have the expectation that contact with health services will increase the risk of notifications to child protection services, a study in Australia found the opposite to be true. Callaghan et al. (2011) reported that engagement with child and family health services resulted in a decreased amount of child protection notifications, and also a higher proportion of substantiated cases of emotional abuse of children in families who had not engaged with the service. Of concern to the authors was the finding that “twenty-three percent of children of substance using mothers were not engaged with child health services at any point during the first two years of life” (p.226). It is not known if the women accessed any other health services for their children or for themselves.

In comparison, the women in the study became more visible in their interactions with services over time. Rather than attempting to limit or conceal their lives from surveillance, the women chose to interact more freely with services. For example, Kristy and Lisa told of how they now felt able to contact child protection services if
they had questions or needed support, whereas in the past this would not have been considered. The findings of other studies has suggested that being visible, thereby allaying the concerns of health professionals, has been a strategy to protect against a higher level of surveillance (Marcellus, 2005; Radcliffe, 2011).

7.4 Resilience

The worst fears of Kristy and Lisa became a reality when child protection services removed children from their care. For me, it was important to gain a better understanding of factors influencing the change in how they interacted with services at the time of the study, given the level of surveillance and ‘set-backs’ they had experienced in the past. The concept of resilience, or the ability to ‘keep on keeping on’ despite adversity, is therefore explored in this section of the discussion. A definition of resilience by East, Jackson, O’Brien & Peters (2010), incorporates the idea of a positive outcome in the face of “detrimental events and experiences” (p.20); not only coping with difficulties, but achieving a useful purpose.

Stories told by women in the study about their history were characterised by hardship and challenges. Their common history included traumatic events, abuse, and/or lack of parental support in early childhood and the teenage years. In addition, there were continuing challenges associated with unstable relationships, inadequate financial resources, housing difficulties and limited support from family or friends. The majority of psychologists studying the long term impact of constant negative experiences have reported that this often results in maladaptive behaviour. In an extensive review entitled, ‘Bad is Stronger than Good’, the authors attempted to challenge their hypothesis that ‘bad’ events have more of an impact than ‘good’ events (Baumeister, Bratslavsky, Finkenauer, & Vohs, 2001). They examined areas ranging from neurological processes to forming impressions and stereotypes. Despite efforts to search for exceptions, and inconsistencies to their hypothesis, the authors found it to be “striking...in no area were we able to find a consistent reversal” (p.354). Of particular interest are the findings related to how impressions are formed through the provision of ‘bad’ information and feedback, and the impact on a positive or negative outlook of health.
Bad stereotypes and reputations are easier to acquire, and harder to shed, than good ones. Bad feedback has stronger effects than good feedback. Bad health has a greater impact on happiness than good health, and health itself is more affected by pessimism (the presence or absence of a negative outlook) than optimism (the presence or absence of a positive outlook) (Baumeister et al., 2001 p.355)

Resilience appeared to underpin the ability of women in the study to have a positive outlook on their lives, and to undertake the work required to ‘shed’ their negative identity as a drug-user. Characteristics of resilience in the literature include the similar concepts of ‘perseverance’ (Wagnild, 2009) and ‘hardiness’ (East et al., 2010), where adversity is accepted as normal, and discouragement is overcome in the effort to “reconstruct one’s life” (Wagnild, 2009 p.16). Hall and Irvine (2009) studying the personal narratives of women survivors of child maltreatment, described resilience in terms of ‘becoming resolute’. Finding meaning and a purpose in life is also a common element of resilience (East et al., 2010; Tarakeshwar, Hansen, Kochman, Fox, & Sikkema, 2006; Wagnild, 2009). In this instance, the women’s purpose was to reconstruct their lives in order to become ‘normal/good’ mothers.

A key concept related to resilience is that of hope, influencing a ‘determination to endure’ despite ongoing adversity (Morse & Doberneck, 1995). The work of Morse & Doberneck (1995) identified seven conceptual components of hope common in a number of contexts, ranging from breastfeeding to waiting for a heart transplant. Hope was defined as a “multidimensional construct that provides comfort while enduring life threats and personal challenges” (p.277). A measure of hope in some way balances negative experiences and challenges through reframing adversity, with an expectation of a future positive outcome.

Exploration of the abstract and complex nature of hope resulted in a framework for considering hope in the clinical setting. Components of the framework, by Morse and Doberneck, include:

- a realistic initial assessment of the predicament or threat
- the envisioning of alternatives and the setting of goals
- bracing for negative outcomes
• a realistic assessment of personal resources and of external conditions and resources
• solicitation of mutually supportive relationships
• continuous evaluation for signs that reinforce the selected goals; and,
• a determination to endure.

Review of stories in the study confirmed the relevance of these conceptual components, as a useful way of thinking about hope and resilience, in relation to women receiving opioid treatment in the perinatal period.

The framework outlined by Morse and Doberneck can be applied to the study findings in the following way. Firstly, the women weighed up the threat to their identity as a mother and clearly described the goal of keeping their child in their care, while still expecting that this may not occur. As stated by Morse and Doberneck (1995), “the fear of a negative outcome provides a motivating force for individual action and makes hope powerful” (p.278); becoming pregnant and risking losing the baby was the ‘turning point’ (Radcliffe 2011) in the women’s stories. The women then considered their chances of success in relation to where they could get support and how they had coped with difficulties in the past. An example of continuous evaluation of goals was provided in Kristy’s story, where she eventually accepted that the best interest of her eldest child was to be in the care of a foster mother. Her ideal goal was not met, however Kristy was able to feel satisfied with a ‘shared motherhood’ with the foster mother as a way of maintaining a good relationship with her son, and provided evidence she was a good mother. This realised hope increased Kristy’s self-esteem, and enhanced her confidence that she would reach her goal of being a good mother for her new baby and toddler.

An important factor in increasing resilience and hope for women in the study was the level of support provided by professionals and family members. A number of authors identify the importance of being connected to professionals in a relationship characterised by trust, mutuality, respect and genuineness (Bartu, Sharp, Ludlow, & Doherty, 2006; Davis & Day, 2010; Marcellus, 2005; Morse & Doberneck, 1995; Thomson & Downe, 2010). The existence of a trusting relationship provides the basis for working on common goals, especially the goal of maintaining the child in the mother’s care. The women in the study returned to key workers who were non-judgemental because they were accepting, listened, and advocated for them. The
threat and uncertainty of surveillance diminished as the level of open discussion increased, and a mutually agreed plan was put in place. Where positive contact with key workers occurred over months and years, a number of the women even shifted in their view of child protection services and described how they might spontaneously contact them for help. Kristy came to the realisation that working in partnership with the services involved in monitoring the care of her child was a much better option than “fighting back” (Virokannas, 2011 p.338), and being in conflict.

Other factors known to influence the resilience of those undergoing adversity include social support and religion/spirituality (Tarakeshwar et al., 2006; Virokannas, 2011). The women in the study did not include religious faith in their stories, although social support from family and friends was an important component of the women ‘staying on track’ and getting through each day. Some women had practical support with childcare and housework from their mother, partner’s mother or their grandmother, as well as the emotional support of being able to talk to someone when life was particularly difficult. Some relationships were re-established with family members when the woman enrolled in the opioid treatment program and engaged with services, providing evidence to family they were doing their best to become a ‘good mother’.

As their identity started to change, the women themselves filtered contact they had with friends and family. Those who provided a risk to their child or to the woman’s new identity were excluded, in order to work towards their goal. For example, Kristy restricted her children’s contact with her “drug addict” mother, to limit the risk they would be influenced by inappropriate mothering. Kristy and other women also indicated they no longer accepted personal relationships characterised by domestic violence, due to their increasing awareness of the impact on the children and their identity as a ‘good mother’; they wanted to break the “vicious cycle” (Kristy) and offer a different life for their children.

Two other concepts associated with changing identity and resilience are described in the work of Thomson and Downe (2010). ‘Being redeemed’ and ‘being transformed’ were key themes emerging from their study of negative experiences related to a previous traumatic birth. A subsequent ‘redemptive birth’ provided the opportunity for “the resolution of distress, guilt and self-blame” and opened the way for ‘picking
up the pieces’ of the “shattered identities” from the women’s earlier experience of trauma (p.107). Similarities are noted with the repair of identities of women who have been involved in substance misuse; ‘redemptive mothering’ is required. Use of biblical language and concepts by Thomson and Downe reinforces the magnitude of the change that occurs in the process of taking on a new identity and life. The theme of ‘being transformed’ is described as where the one who is redeemed moves “from a state of dis-grace to a state of grace...memories of trauma forgiven, but not forgotten” (p.107). These concepts were also clearly found in the stories of women in the study where hope was able to overcome judgement and provided a future view that the disgrace and ‘sin’ of being a drug addict could be overcome through ‘redemptive’ mothering. An example of this is shown in Nicole’s story of persisting with breastfeeding, despite multiple barriers, and the satisfaction she felt from achieving her goal to breastfeed. If there is no hope of redemption and transformation, the consequences can be detrimental to the woman and the child. Feelings of inadequacy are reinforced, and the energy required to be resilient is lost; in the words of Thomas Fuller (1608 – 1661), “Without hope the heart would break”.

7.5 The Hope of a Better Future

The women in the study identified that pregnancy and having a new baby provided them with the opportunity to move away from the culture and dependency of drug use. Despite the challenges associated with remaining on an opioid treatment program, the women recognised that treatment and support brought them closer to their goal of a better future. The alternative was a possible return to the cycle of drug-use, with long-term and detrimental effects on their health and relationships. Of most importance to the women was a future where they were able to provide for the needs of their child/children. Radcliffe (2011), refers to the desire of women receiving treatment for substance use to have a normal family life and to at least be recognised as “plausible mothers” (p.990). The first step in this process was “by becoming clean” (Radcliffe, 2011 p.986). Bessant (2004) also described the goal of women in her study as being able to look after themselves and their children, which is similar to other studies reporting on the experiences of women receiving treatment for substance use. A future where they were able to ‘keep’ their child rather than
have the child ‘taken’ from their custody, and have some certainty they were meeting the requirements of child protection services.

Breaking the hold of intergenerational issues, to gain a better future, was important to those women in the study who had experienced a childhood characterised by physical and emotional abuse. For example, Kristy recognised the necessity of breaking the ‘vicious cycle’ and her determination for a better future is reflected in the words, “No more...I’m going to change this and make it”. Kristy recognised the support she had received over many years from her case manager, psychologist, and later by child protection workers had brought her to the point of feeling able to be change her circumstances. The increasing sense of self as a worthwhile person experienced by Kristy and other women in the study is acknowledged, as it was not easy for them to move away from unsupportive and violent relationships to improve the future for themselves and their children.

The transformation required for a better future for women receiving opioid treatment in the perinatal period is a fragile process and takes time. As discussed in the previous section, resilience and hope are components supporting a positive change, and the ability to move forward is also influenced by relationships that develop with health and child protection services. Etherington (2007), identified that some relationships may be prematurely described as a ‘partnership’. In reality the balance of power is changeable, requiring an ongoing commitment by health professionals, for a level of partnership to be maintained. If this is not recognised, there may be limitations in the effectiveness of the relationship. Acknowledgement of the client as a person, rather than someone with a problem, provides the message that they are “important enough to work with collaboratively” (O’Brien, 2001 p.183), and lays the foundation for the development of a therapeutic relationship. Ettorre (2004) calls for the ‘revisioning’ of the traditional and stereotypically negative and damaging views commonly held of women and drug use. In doing so, services are more likely to gain a “multi-levelled view” of the women’s issues and challenges, and provide holistic care (Ettorre, 2004 p.333).

The intrinsic authoritative power vested in health professionals requires mitigation if families are to have a voice in their care, and for collaboration and partnership to become a reality. A number of authors refer to the importance of ‘empowerment’ to
enable engagement on a more equitable basis (Bessant, 2004; Mitcheson & Cowley, 2003; Normandale, 2001). The women in the study described relationships where they felt listened to and respected, and where they felt comfortable to ask questions about their child and seek help. The terms ‘client-centred care’, ‘woman-centred care’ and ‘person-centred care’ have become synonymous with a strengths-based and partnership approach. Keys (2007) discusses how the young women in her study described their hopes and goals, however most had no definite plans of how they might achieve such goals. Working in partnership with families provides the opportunity for professionals to not only listen and understand the woman’s concerns in a non-judgemental way, but to also take the extra step of considering and implementing strategies to meet future goals (Davis & Day, 2010; Lefebvre et al., 2010).

Asking for help is seen as a feature of ‘responsible motherhood’ (Virokannas 2011) and could be considered as an indicator of the development of a trusting relationship with services. Ettorre (2004) describes a harm reduction approach utilised in Dublin where the service was not only respectful and flexible to the needs of women, but also incorporated a gender-sensitive approach recognising the need to develop confidence and self-esteem in female identities. If the relationship is not open and honest, silence can be imposed, or applied by choice (Carpenter & Austin, 2007). As a result, the voice of vulnerable clients is not heard, and the ability of services to respond in a useful way is limited. It seems that service providers may also benefit from working to change their identity.

Acceptance by professionals, and advocacy on their behalf, is very important to women with a history of problem substance use on their journey towards becoming a ‘normal’ mother. Polansky et al. (2006) reported on an attachment-based parenting group for mothers with drug addictions, and found that a “profound sense of security” (p.118) was associated with being understood and accepted by health professionals (Polansky, Lauterbach, Litzke, Coulter, & Sommers, 2006). Assisting with parenting skills is identified as a key area of support by services (Keys, 2007), especially if women have not had any positive parenting models in their own lives, and are likely to have difficulty raising their own children (Polansky et al 2006). Women in a study by Dawe (2007) recognised the negative impact on their ability to care for their child if they had not had a secure attachment to their own parents.
7.5.1 The importance of recognising the needs of, and providing services for children

Problem substance use has implications for the child from the time of conception, and health services aim to provide universal as well as targeted antenatal and postnatal care to women to reduce the impact on the child (NSW Department of Health, 2006). An extensive report in the United Kingdom in 2003, ‘Hidden Harm’ brought out into the open the little researched area of the impact of parental substance use on children. Recommendations were made to further investigate this area, and provide services with a focus on prevention (ACMD, 2003). In Australia, investigations regarding the impact and implications of drug use in the family were presented by Dawe et al. in 2007. In both reports, the importance of developing protective factors in the child was discussed to promote resilience, and improve circumstances for optimal growth and development.

The development of preventative services has gained momentum in response to the deaths of children; an issue that cannot be dismissed. Investigations into all child deaths, by the NSW Child Death Review Team, have found an association between some deaths and parental substance misuse. Following the tragic death in 2007, of two children known to child protection services, the NSW Government commissioned a ‘Special Commission of Inquiry into Child Protection Services in NSW’. The subsequent report made recommendations to build on existing preventative strategies, such as the ‘Brighter Futures’ program which commenced in 2002. Key recommendations of the inquiry included the need to improve the identification of significant risk of harm to children, and the communication of information between services. The subsequent release of the policy document, ‘Keep Them Safe: A Shared Approach to Child Well-being 2009-2014’ (NSW Department of Health, 2009a) provides assistance to mandatory reporters in the identification of significant risk of harm, and incorporates processes for the sharing of information between agencies, including those in the non-government sector. Collaboration between services is an essential component of improving the safety, and physical and emotional health of children necessary for a better future.

Although the responsibility for the care of children ideally rests with parents, there are occasions when it is not safe for a child to remain in their care. A report considering the current social environment for Australian children (Parkinson, 2011)
raised concerns about the number of children who live in out-of-home care, due to safety concerns. For many of these children, parental problem substance use and mental health issues were factors in removal from the care of their parents. Parkinson (2011) reported that the number of children in out-of-home care in Australia has doubled in the period 1997-2009, and the Council of Australian Governments (COAG) estimated that in 2009 over $2 billion was spent on child protection services.

If a better future is to be available for the children of women receiving opioid treatment, ongoing review of services and individual professional practice is required. The postnatal period has been described as a “child-centred crucible of risk” (Zadoroznyl, 2006 p. 361) and some models of care have focused on responding to identified ‘deficits’ (Radcliffe, 2009). Instead, flexible models of care, based on the women’s needs and recognition of protective factors, need to be considered and advanced in collaboration with families and local networks of service providers. The success of any model of care is dependent on the quality of the relationship between individual professionals and the clients of the service. A partnership that builds on “positive attitudes, hopes, values and capabilities” (Etherington, 2007 p.77) can provide the cornerstone for a better future for both women and their children. This view is similar to that of Davis & Day (2010) who included the following quote on the dedication page of their book on working in partnership with families,

"...for a long time to come he’d have reason to evoke the recollection of those smiles, and to reflect upon the goodwill which provoked them, for it had the power to protect and to confer honour, and to strengthen resolve, and it had power to heal and to bring them to safety long after all other resources were exhausted."

(McCarthy, 1993)

As a clinician, it is encouraging to know that even if health and other resources are limited or not available, useful support can be provided during each interaction with a client, yet this takes time. The value of clinicians responding to clients in a positive way is difficult to measure; however, a human connection with those we aim to support can increase their capacity to move forward and achieve their goals.
7.6 Summary

This chapter has considered the significance of the study findings in light of other knowledge and provides a deeper understanding of factors that act as barriers or facilitate the use of services by women receiving opioid treatment in the perinatal period. The first key area for discussion was the concept of identity, and the importance to the women of being a ‘good’ or ‘normal’ mother. The stigma attached to being a drug user and a mother was considered along with the challenge to change their identity away from that of a ‘junkie’ and ‘deviant’. The women felt guilty about the impact of their previous drug use on their child, and responded quickly, and negatively to any indication that they were being judged. It was evident that the women needed to work hard at their ‘moral career’ to become acceptable as mothers.

The concept of surveillance linked to that of identity, and was discussed in the second section of the chapter in light of the women feeling watched and more readily judged in comparison to other women. The more overt power of child protection services, as well as the inherent power of all health professionals due to their mandatory reporting responsibilities, was a major concern of the women in the study. Any report to child protection services put their motherhood at risk.

The third and fourth sections of the discussion considered resilience and the hope of a better future. The women wanted to be ‘good mothers’ and the section on resilience explored the challenges of overcoming adversity to achieve their goal of maintaining custody of their child. Within this section, hope was explored and found to be a vital component of resilience. A changing identity is difficult to achieve without support, and the final section considered how services might work together with women receiving opioid treatment and advocate for them. The section concluded by considering the impact on children if support is not available to women receiving opioid treatment, followed by a reminder of the importance and value of each positive interaction with clients.
CHAPTER EIGHT

CONCLUSION

In this thesis I have used narrative inquiry to report and interpret the stories of six women receiving opioid treatment. In-depth qualitative data was obtained from listening to the women’s experiences of seeking and or receiving health and child protection services in the perinatal period; a recognised time of life transition. The women’s stories included their experience with a range of health professionals and services providing care and support. For example, drug and alcohol services, universal health services in the acute and community setting, and child protection services. This final chapter concludes the thesis by reviewing the rationale for undertaking the study, the value of the chosen methodology, and the key findings, the themes of judgement and hope. I also consider how the perspective of the women receiving opioid treatment adds to existing knowledge, and the implications for clinical services. The study is not without limitations and these are also discussed in this chapter, as well as recommendations for future research.

8.1 Rationale for the study

International research and government policy has previously highlighted the importance of providing support to families affected by problem substance use. In addition, further research in this area has been recommended in order to provide guidance for service development. Women receiving opioid treatment in the perinatal period are known to have a high level of complex needs due to their history of problem substance use and related co-existing personal and situational factors; and yet they do not typically access traditional health services. The aim of the study was to determine how women made meaning of their interactions with services by analysing the narratives of six women’s experiences. In doing so, the factors that acted as barriers or enabled service access were examined. As a child and family
health nurse, with a midwifery background, I wanted to understand the women’s perspective of their experiences across the continuum of care from pregnancy to the end of their child’s first year of life. How can services be strengthened with a view to improving outcomes for the women and their children?

8.2 The value of a narrative methodology

Narrative Inquiry was an appropriate and valuable methodology for the study as it allowed the participants to tell their perspective of interactions with services in the perinatal period. The effectiveness of the methodology was demonstrated by the richness of the data collected from listening to the individual story of each participant. The women’s stories were consistent at both interviews, despite a gap of 2-6 months between the first and second interviews, and each contributed to a collective story of the experiences of this population of women with a high level of need and vulnerability. Support from drug and alcohol staff to recruit participants, and the ability to interview the women at the opioid treatment clinic, assisted in achieving one hundred percent retention of the participants in the study. This encouraging response could also be attributed to the development of a trusting relationship with the women in the process of organising and undertaking the interviews.

Following the lead of the participants was very important to the data collection and subsequent analysis. The individual stories of the women were also part of a larger collective story which revealed cultural meanings for that group of women. The stories had a turning point – pregnancy and birth, and moral issues such as prejudice and discrimination, and the impact of power relations were identified. A human connection characterised by non-judgement, listening and empathy ameliorated, in part, negative experiences of services. It was challenging for me to present the findings of the study and maintain the integrity of the individual stories. This was due in part to the connection I felt to the women. ‘Nina’s Story’ represented a collective and more chronological depiction of the story of the women across the perinatal period, before the data was separated more clearly into the two main themes of judgement and hope.
Active and ongoing reflection of my role as the researcher in the research process, described as critical reflexivity, was an important component of the data collection, data analysis and presentation of the findings. I could not exclude my presence from the research process, a dilemma noted by Mantzoukas (2004), in regard to qualitative research, but instead I aimed to openly describe and acknowledge my role in the process. For example, my response to feelings of frustration in the interview where I did not seem to be obtaining the data I ‘wanted’.

In addition, I have been aware my professional role as a child and family health nurse could potentially influence the study, and have endeavoured to present the findings in a way that closely reflect the meaning of the women’s stories of their experiences with services. The privilege of listening to the women’s stories brought responsibility for how the data was analysed and presented. Although it was not comfortable for me to hear of the women’s negative experiences, I endeavoured to keep the same balance of negative and positive experiences in the study findings, as described by the women. Through critical reflexivity, I have observed parallels between the research process and clinical practice – engagement, listening, being respectful and understanding, valuing the participant; reflection about practice and reflection in practice.

8.3 Judgement and hope

Analysis of the data resulted in two key themes – judgement and hope. The theme of judgement, linked to negative experiences of services, and included aspects of self-judgement. Fear of the involvement of child protection services and the possible loss of custody of their child was a strong element of this theme. In contrast, the theme of hope incorporated the desire for a changed identity and a new life. The women wanted a fresh start and articulated their good intent towards their baby. Positive experiences with services reinforced feelings of hope and the idea that life with this baby could be different from their own history, or from previous experiences with other children who had been removed from their care. The juxtaposition of judgement and hope was present in the women’s stories and this was reflected in the findings chapters.
Identification of the themes of judgement and hope led to consideration of the concepts of identity, surveillance, resilience and a better future. The impact of stigma on a social level and the difficulty in changing identity from a drug user to a good mother was explored. Society tends to apportion blame on individuals for being drug users and not helping themselves, however recent research has found that a high proportion of women using illicit drugs have a history of physical and sexual abuse, where sexual abuse occurred at an average age of 10 years (Taplin & Mattick, 2011). The individual circumstances and previous experiences of women, which often includes abuse, impacts on the way they interact with services. It is therefore important for services to respond to the individual needs of women receiving opioid treatment, and provide care that creates hope instead of judgement.

8.4 Implications for services

The women in the study were very aware of the power inherent in the roles of any group of health professionals, as well as child protection workers. Yet the women’s ultimate fear of losing the custody of their child was found to diminish over time where professional knowledge and support, or links to support was provided with a level of flexibility to meet the individual needs of the women. The health and best interest of the child must always take priority over the good intentions of mothers where there is evidence of abuse and/or neglect. However, this study has shown that change is possible with ongoing support from health professionals who demonstrate a non-judgemental and positive attitude, work from a strengths-based perspective, and provide support and advocacy to women. It is to be expected that there will be many challenges in meeting the women’s needs, and that time is required for a trusting relationship to develop. The key for change was the women’s desire to be a good mother and break the ‘vicious cycle’ of intergenerational drug use.

This study has provided greater insight into the perspective of ‘consumers’ of health services in the perinatal period, and this knowledge can be used to inform and develop services to better meet the need of women receiving opioid treatment. Resilience and hope for a better future increases where services are client-focused and move beyond identifying risk and vulnerability, to build on protective factors such as wanting to be a good mother. One implication for services is to consider
how to develop and sustain qualities and skills needed by health professionals to provide support in the context of the women ‘being a mother’, and also requiring opioid treatment. Where listening and respect was central to interactions with health professionals, the effect of previous judgement or negative experiences was diminished. As suggested by women in the study, education about opioid treatment and management would assist staff, especially those providing universal services who have less knowledge and involvement with this group of women, to respond to the women as ‘normal mothers’. This, participants stated, would enable them to ask questions about pregnancy, birth, their baby and parenting.

Working in partnership with women receiving opioid treatment in the perinatal period can be very challenging, particularly due to the tension of providing support, as well as having a mandated role in reporting child safety concerns. Regular clinical supervision can assist staff to reflect on their interactions with clients and work through challenges that have the potential to impact on client care and worker ‘burn-out’. Health services therefore need to consider how they will provide clinical supervision, and education, for health professionals.

On a service system level, the study supports the concept of integrated models of care in improving access and support for women receiving opioid treatment in the perinatal period. To date, it has proved challenging for services to establish collaborative services relevant to local needs. What agreements can be reached regarding a strengths-based approach to care and what does this mean in practical terms when providing support? How can universal health services, drug and alcohol services and child protection services improve collaboration and care provided to this group of women and how will services know if this has been achieved? ‘Consumer participation’ is central to the review and the reorientation of health services. It is important for services to consider how they will respond to calls for gender-sensitive services, and include women receiving opioid treatment in this process.

8.5 Limitations

The study has a number of limitations as the findings are particular to the stories of only six women who were interviewed on two separate occasions in one Australian State Area Health Service. Furthermore, the women self-selected as participants of
the study, and their experiences of services in the perinatal period may be very different from the experiences of other women receiving opioid treatment at that time. It is most likely that these women felt more positive and confident about interacting with the health service and as a result were keen to tell their story. The small number of participants in the study and the lack of representation of women from an Indigenous or culturally and linguistically diverse background also limit the ability to generalise the findings to other settings.

My interpretation of the women’s stories and the meanings they placed on their interactions with services may not be completely true to them; however, use of critical reflexivity has sought to minimise this limitation.

8.6 Recommendations for future research

Future research is needed to build on existing knowledge and provide evidence to more clearly determine ‘best practice’ regarding supporting women receiving opioid treatment in the perinatal period. Based on the findings and limitations of this study, recommendations for future research include:

- larger studies in Australia and overseas of the experience of women receiving opioid treatment and support in the perinatal period
- comparative studies of women receiving opioid treatment from private clinics or pharmacies in the perinatal period
- use of a narrative methodology for women from indigenous and culturally diverse backgrounds
- prospective research on the experiences of women as they receive opioid treatment and universal health services in the perinatal period, particularly examining outcomes related to maternal mental health and parent-infant attachment
- further exploration of women’s identity as a mother, particularly for those who share mothering with another, such as foster parents
- development of integrated models of care for women receiving opioid treatment, rather than for both men and women
- understandings of health professionals regarding obstacles to providing care
• examining the experiences of mothers and grandmothers of women receiving opioid treatment who are providing support and caring for children.

8.7 Summary

The themes of judgement and hope and evidence of negative and positive experiences of services has corroborated previous research in this area. However, a key point of difference from previous work is evidence of the overarching significance of motherhood to the women and their articulation of wanting to change their identity from a drug user to a good mother. This knowledge provides a ‘way in’ to engaging with women that might otherwise be overlooked. In addition, the study has considered the women’s experience from pregnancy until the first year of their baby’s life, rather than their experiences of services only during pregnancy or the postnatal period. In doing so, a broader and more in-depth understanding has been gained of the women’s experiences at this time of transition in their lives. The evidence presented in the women’s stories has raised questions for health services and governments of how best to provide services for women and children when opioid treatment is required.

Many threads were interwoven between all the stories with an ultimate picture of judgement and hope, where hope can prevail. The capacity for a better future from the findings in this study are influenced by the contact services have with this marginalised group of women and have relevance to other marginalised groups. Hearing and sharing the stories of six women receiving opioid treatment has been a privilege. It has been encouraging to see that services can make a difference, and the findings provide feedback to others in the ‘helping’ professions.

A metaphor was introduced in chapter three where the women’s stories were likened to a patchwork quilt, not neat and tidy, but where each story or piece of fabric sat alongside other stories, and where commonalities brought them together. I would now like to extend the metaphor as the women’s stories seem to be more to be like a rich tapestry or collage; the depth of the data now provides a three dimensional representation of their stories. Exploration for a suitable image to represent this idea led me to the work of Sue Benner, an expert in ‘Quilt Art’. Sue’s interest in the
theme of motherhood and multiple layers of meaning, link in well with the study methodology, findings and reflections.

The following, and final pages of this thesis, contain an example of Sue Benner’s work from her ‘NEST Series’ (Benner, 2003) and a brief reflection on the imagery in relation to motherhood and the findings of the study. Individual stories, or parts of the ‘quilt’, have come together in a larger collective story with implications on many levels. For me, the challenge to present the women’s stories has been worth the journey. It is my hope this thesis will provide additional insight to services endeavouring to respond to the needs of women receiving opioid treatment in the perinatal period.
Sue Benner: Artist
NEST IV
2003 - 62" x 46.5"
dye and paint on silk, fused, mono-printed, machine quilted
Private Collection, St. Louis, MO
Artist’s statement: ‘NEST Series’

I have periodically approached the subject of motherhood in my work. One winter, my two sons found a nest that had fallen from a tree in our yard. I put the nest in my studio and soon my quilts became nests. I see an image of home and centre in this series but others see hurricanes and galaxies. I like that.

My Reflections

The work of Sue Brenner, and her story as described in the ‘Artist’s Statement’, is a fitting conclusion to this thesis. ‘Nest IV’ creatively displays concepts that emerged from the stories told to me, and have been presented in this thesis in the form of written text. For me, ‘NEST IV’ encapsulates the desire of the women to be nurturing, ‘good’ mothers amongst the challenges of their lives - the ‘hurricane’ perspective. The circular ‘nests’ remind me of the ecological framework needed to support women with complex needs during the perinatal period. I also see judgement and hope, the two main themes of the study, in the darker tones and lines, and the contrasting areas of light. My eye is drawn to the central area of light representing the women’s hope for a better future for their children and themselves.
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APPENDICES
Appendix 1

JOURNAL ARTICLE

Harvey, S., Schmied, V., Nicholls, D., Dahlen, H (in press)

Key components of a service model of care providing early childhood support for women attending opioid treatment clinics: An Australian State Health Service Review

Journal of Clinical Nursing – uncorrected proof
ORIGINAL ARTICLE

Key components of a service model providing early childhood support for women attending opioid treatment clinics: An Australian State Health Service Review

Susan Rosalind Harvey, Virginia Schmied, Daniel Nicholls and Hannah Dahlen

Aims. To report the findings of a service review – specifically the strategy to provide early childhood services ‘on site’ at opioid treatment clinics to address access difficulties.

Background. Child and family health nurses are skilled in the assessment and support of families during early childhood. However, women with a history of substance abuse are often cautious when engaging with universal and other health services, with the result that the infant may miss recommended developmental screening and early referral to improve health outcomes.

Design. In 2006, an internal review was undertaken of the integration of early childhood and parenting services at opioid treatment clinics in a large Area Health Service of New South Wales, Australia.

Method. A qualitative study design, using semi-structured interview questions was used. Data were collected via six focus groups (4–15 participants in each group) and individual interview of child and family health nurses, nurse unit managers and clinical staff (n = 58).

Results. Three key components of a model for providing early childhood support in collaboration with opioid treatment services were identified. First, the importance of building a trusting relationship between the woman and the child and family health nurse; second, maintaining continuity of care and a multidisciplinary/multiagency approach; and third, the importance of staff education, support and professional development.

Conclusion. The provision of early childhood and parenting services on site, as part of a multidisciplinary ‘one stop shop’ approach to service delivery was a clear recommendation of the review.

Relevance to clinical practice. Reduction of access difficulties to specialized early childhood support is of benefit to clients, community health services attempting to provide a service to this difficult to reach population and to drug and alcohol services seeking to provide a high level of holistic care for clients.

Key words: child and family health, nursing, integrated model of care, opioids, substance abuse

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Introduction

Becoming a parent is a life transition and the early weeks and months after birth are a recognised time of ‘physical, psychological and social upheaval’ (Rodrigues & des Rivons-Pigeon 2007). At this time many parents report a lack of confidence and knowledge regarding normal infant behaviour and the management of feeding and settling issues (Fonnet et al. 2007) and 10–15% of women in Australia experience postnatal distress and depression (Ruiz et al. 2008). Women who have experienced substance misuse often face additional challenges in early parenting including poverty, isolation and mental health issues and therefore, may have less capacity to care for, interact positively with their infant, (Fonnet et al.)

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2007) and enjoy being a parent due to the added impact of their own issues and needs. In some cases, inadequate care and supervision has resulted in injury or death of infants, with an increased risk to children in households where there is drug and alcohol use, domestic violence and crime (NSW Child Death Review Team 2009).

The importance of ‘responsive parenting’ in the development of the child has been shown through research on early brain development (McCain & Massad 1999, Oberklaid 2006, Swain et al. 2007) and parent–infant attachment (Bowlby 1988, Horowitz et al. 2005, Stevenson-Hinde 2007). A secure attachment to the primary care-giver provides a buffer against early adversity and psychosocial factors such as poverty, parental substance use, mental illness and exposure to violence. Intervening as early as possible can improve outcomes for infants and reduce the risk of long term health problems including depression, alcoholism, heart disease and diabetes (Perry 1997, National Scientific Council on the Developing Child 2005). Prevention and early intervention significantly reduce the economic cost to the community as later interventions are shown to be less successful and even ineffective (Oberklaid 2006, Council of Australian Governments 2009).

Research has also identified that opportunities exist in the first few years of life to improve outcomes for children if less than optimal early stimulation has occurred (Wilkinson 2004), providing the impetus for regular child development screening, diagnostic assessment and treatment and parenting support in the early childhood period.

However, women with identifiable vulnerabilities associated with substance use may be cautious when engaging with child and family health services, as they may feel, or indeed be acutely aware, that they are ‘under surveillance’ (Pecilehov 2002, Jack et al. 2005, Manellig 2005). Some women are already clients of multiple services prior to pregnancy for example, as a result of previous assessment and treatment for mental health or drug and alcohol issues (Barlow et al. 2005, Manellig 2005). In addition, previous children may have been removed from the care of the woman by child protection services for child safety concerns, influencing their decision to engage with services.

Australian Context of child and family health nursing services

In Australia, CFHNSs, (also known as maternal and child health nurses in some States) have a similar role to health visitors in the UK, child health nurses in Sweden and Public health nurses in New Zealand. In New South Wales (NSW), Australia a key component of mainstream child and family health nursing services is the offer of a home visit to all women within two weeks of the birth of their baby. Early childhood health clinics are available for ongoing support in parenting and regular developmental assessment of the infant/child until school entry. CFHNSs are uniquely placed to identify vulnerabilities and protective factors, increase parenting knowledge, scores for developmental delay (physical and psycho-social), provide brief interventions and advocate for the infant and family in accessing further support and negotiating health systems.

Models of care for women receiving opioid treatment

Traditionally drug and alcohol services and child and family health nursing services are provided separately to families. However, integrated models of care in pregnancy and after birth are emerging as best practice to reduce barriers for women with a history of substance use to access health and support services (Kaltenbach 2009, Lefebvre et al. 2010). The 2004 United Nations Report, Substance Abuse Treatment and Care of Women states that ‘ideal services should be accessed through a single site’ to improve outcomes for women who are pregnant or who have children in their care. Internationally, some evidence reports the benefits of integrated programs compared with non-integrated programs however, the limited evidence was not available at the time of the Ana Health Service (AHS) Review. Two meta-analyses considered the benefits of integrated programs in improving maternal mental health (Nicols et al. 2010a, b) and in reducing the level of maternal substance use (Milligan et al. 2010). The few integrated programs included in the analyses demonstrated a small positive effect on mental health (Nicols et al. 2010a, b) and reduction in the level of substance misuse (Milligan et al. 2010a, b) but the benefits for children was not reported. In 2007, a national survey of services in Canada providing substance use treatment to women identified that approximately half of the respondents offered a pregnancy, parenting or child-related service, with the majority of services delivered by way of external referrals. However, very few agencies provided any services for children under five years (Nicols et al. 2010a, b) and throughout the available literature there is little discussion of integrated or non-integrated programs and the impact on outcomes for the infant or child.

Background to the review

The AHS in NSW where the review took place has a population of approximately one million residents and 18,000 births per year. Notable socio-economic differences
As a result the AHS drug and alcohol service identified a need to improve access to early childhood health services for clients of opioid treatment clinics with children 0-5 years. A partnership was negotiated between community health services, a local major children's hospital and drug and alcohol services to provide key components of early childhood health services at opioid treatment facilities. Early childhood health services commenced in 2001 at one site and were gradually expanded to other opioid treatment services over three years. The number of hours of support from a CFHN ranged from 4-20 hours per week, dependent on the site. The support included provision of recommended child development assessments, as well as the opportunity for parents to ask questions about any concerns with their infant and to receive support with parenting. At some venues immunisation and a playgroup were also available. Referrals were made to more specialised services as required, such as speech pathology, occupational therapy, a parent-infant therapist and a residential unit providing further support with feeding and sleep difficulties. In addition, funding was provided for the establishment of a supported playgroup at one site in partnership with NSW child protection services. Previous evaluation of early childhood and parenting services at opioid treatment clinics had occurred as individual sites and in response to funding requirements. However, a comprehensive evaluation had not been undertaken across all sites until the review in 2006. The aim of this article is to report the findings of the service review—specifically the strategies developed to provide early childhood services on-site at opioid treatment clinics to address barriers to accessing mainstream services.

Methods

The review was undertaken as a quality assurance project in accordance with the ethical principles contained in the Declaration of Helsinki (WMA 2008) and national guidelines for the conduct of research in Australia (NHMRC 1999, Australian Health Ethics Committee 2002). Consent was provided by the AHS and the research principles of privacy, integrity and beneficence were followed throughout the review. The first author, employed as a Child & Family Health Clinical Nurse Specialist at the time of the review, was seconded to the Drug and Alcohol Network to facilitate consultations and provide recommendations. A Steering Committee of key stakeholders provided guidance and oversight.

A qualitative study design, with semi-structured interview and focus group questions was used to obtain the experiences of child and family health nurses and registered nurses providing pharmacotherapy and case management at the opioid treatment clinics. Descriptive content analysis was used to determine the results of the review, described in this article. All identifying elements have been removed and content has been obtained from the AHS to publish findings.

Participants

A total of 58 clinicians and managers participated in individual interviews or focus groups. Individual interviews were offered to staff members identified by the Steering Committee as key participants for the review. This included four CFHNs providing early childhood services and the five Nurse Unit Managers (NURs) of opioid treatment services in the AHS Other clinicians and managers involved in the continuum of care from hospital to community-based services, such as Drug & Alcohol Counselling/Liaison staff, psychologists, medical officers and managers, were also interviewed. The potential participants were contacted by phone or email and interviews were arranged. The focus groups were held at the opioid treatment clinics and comprised 4-15 participants. All staff members available on the day were invited to attend the focus groups.

Data collection

The first author facilitated the data collection and the majority of the data were collected via six focus groups. Prior to each focus group and individual interview participants were provided with key prompting questions such as:

- How are early childhood and parenting services currently delivered to women who attend opioid treatment clinics?
- Describe what works well in the provision of early childhood and parenting services.
- Describe any difficulties in service provision.
- What additional services are required to meet client needs?
S K Harvey

- Describe links to other agencies involved in the client's care.
- What would you include on a 'Wish List' to improve service provision?

Focus groups were one hour in duration and interviews lasted between 30-60 minutes.

Data analysis

Descriptive content analysis was used to examine and categorise the data obtained from the key prompts/questions to staff during focus groups and individual interviews. The analysis was guided by steps outlined by Elo and Kyngas (2008) and commonly used by qualitative researchers. First, the process involved making sense of the data by becoming completely familiar with them. The next phase was to identify and label the main topics or issues discussed and then to categorise these. Further analysis identified strategies for providing early childhood support in conjunction with opioid treatment services (see Table 1). The data analysis was limited to a descriptive goal of presenting data generated by individual interview and focus groups which limited the conclusions (Neuendorf 2002) to early childhood and parenting services in the particular AHS. Core elements of the model of care emerged from the data and were presented to staff for confirmation.

Results

Three key issues (themes) were identified through the qualitative content analysis. These themes provided a framework for a model of care providing early childhood support in conjunction with opioid treatment services. The themes are as follows: first, the importance of building a trusting relationship between the woman and the child and family health nurse; second, maintaining continuity of care and a multidisciplinary/interagency approach; and third, the importance of staff education, support and professional development. These themes will now be elaborated.

The importance of building a trusting relationship between the woman and the child and family health nurse

Participants in the review emphasised that building a trusting relationship was central to the woman engaging with child and family health nursing services. The terms 'engaging' and 'engagement' are commonly used by health professionals and in this instance was used by participants and the researcher when referring to promoting the involvement of women in services. Several factors contribute to how quickly the woman is prepared to trust the CFHN and 'commit' to building the relationship:

Word spreads when clients feel that the staff can be trusted – this encourages other parents from the Methadone Clinic to have contact with us (CFHN)

When a trusting relationship is established, more effective support can be provided as the nurse and the woman work together on strategies that meet the needs of the family.

Strategies for building a trusting relationship over time

Three strategies were identified to build a trusting relationship between the woman and the child and family health nurse:

1. Antenatal engagement

- Staff directly involved in providing early childhood services to women attending opioid treatment clinics identified that antenatal contact with a CFHN increased the likelihood that

<table>
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<th>Theme</th>
<th>Strategies</th>
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<td>Engagement trust relationship</td>
<td>The importance of building a trusting relationship between the woman and the CFHN</td>
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<td>What works well/difficulties in providing early childhood support</td>
<td>Continuity of care and a multidisciplinary and interagency approach</td>
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<tr>
<td>Staff support</td>
<td>Education, support and professional development to enhance care and retain experienced staff</td>
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women would engage with the service in the postnatal period. The antenatal contact may have been intentional, with the CHFN introducing herself to the mother during her antenatal clinic appointment at the hospital, or it may have occurred opportunistically at the opioid treatment clinic (also known as a ‘Methadone Clinic’). The participants believed that even one contact with the woman antenatally provided the basis for development of a positive relationship with the nurse:

I’ve met some women at the high risk antenatal clinic...that helped when I saw them again after they’d had the baby...they were more likely to talk to me. (CHFN)

(2) Engagement during the dispensing of pharmacotherapy

At three of the five opioid treatment clinics, the CHFN made deliberate contact with mothers during the dispensing of pharmacotherapy. This engagement strategy emerged following unsuccessful attempts to operate a regular ‘Baby Clinic’ at two of the opioid treatment clinics on the day the CHFN was present. In both cases, staff considered that the women were suspicious of the nurse and her motives, where the ‘surveillance’ role of the nurse (with requirements to report ‘risk of harm’ to child protection services) was perceived to be greater than possible support from the nurse.

A less direct approach, where the CHFN was present as the second nurse at the dispensing of pharmacotherapy, allowed the development of a support with the woman over time. It also provided the opportunity to observe any infants or children accompanying the woman to the clinic. CHFNs found that the women became more at ease with their presence ‘at the window’, which allowed written and verbal advice to be given informally. The emerging relationship with the woman during dispensing of pharmacotherapy subsequently allowed informal discussions around feeding questions in relation to normal infant development. These discussions took place in the waiting room of one opioid treatment clinic. It was reported that the discussions were not impeded by the presence of other women, who also listened and contributed at times. Individual and confidential parenting support was also offered in a separate room of the same clinic and accepted by some women as a result of the development of the trusting relationship with the child and family health nurse:

They got used to seeing me at the window and I could talk to them about how things were going with their baby. (CHFN)

(3) Engagement during home visits in the postnatal and early childhood period

The ability to provide home visits in the postnatal and early childhood period was found to be a useful strategy to provide support targeted to the needs of the woman. Greater time and opportunity to understand the context of the family and their needs and for the woman to ask questions in her own environment strengthened the relationship with the child and family health nurse. Joint home visits with a registered nurse from the Drug & Alcohol Network also improved the woman's trust of the multidisciplinary team. This strategy also gave a clear message to clients that there was sharing of information between services which promoted common goals of care for the woman and infant:

...using the mother at home helped me understand how hard it is for her...I just try and listen and let her talk. I try not to comment on how tidy the house is...she asks me questions about the baby and the toddler. (CHFN)

Continuity of care and a multidisciplinary/interagency approach

Linkage of services and support provided to the woman antenatally, postnataally and in the early childhood period was identified as the second key component of providing early childhood support. Care was enhanced when the CHFN was able to attend hospital ‘discharge planning’ meetings with representatives from antenatal, birthing unit, postnatal, drug and alcohol, social work and child protection services. Contact with women and services antenatally also contributed to the transition from hospital to community-based services. The woman was aware of child and family nursing services available following the birth of her baby and was more likely to accept a home visit and/or other support than if there had been no antenatal contact. In addition, midwives reported increased confidence that the woman would remain connected to health services, resulting in a reduced level of professional concern for the woman and infant as they were discharged from hospital.

Participants identified the benefits of a multidisciplinary team approach within the Drug and Alcohol Network. Inclusion of the CHFN to 'the team' contributed to improved communication regarding the needs of the family and the provision of holistic care. Team members reported an increased understanding of the plan of care for the woman and her children:

...it’s also good for the whole team...you’re able to be more aware and look at the whole picture. (Name Unit Manager, Opioid Treatment Clinic)

...it’s good when you can trust another worker’s judgement. (Drug & Alcohol worker)

The coordination of ‘support’ was also improved, reducing the impact on the family and the woman’s feelings of being
overwhelmed by the expectations of different aspects of the service. It was identified that appointments with other services were often missed when clients needed to travel elsewhere, before or after receiving their pharmacotherapy. This also impacted on the success of referrals to mainstream child and family health nursing services, including universal and sustained home visiting. The concept of a ‘one-stop shop’, when women can access early childhood services, pharmacotherapy, case management and multidisciplinary services, was well supported by staff.

Links with other agencies such as child protection services were enhanced when clear communication processes were established and common aims were articulated. It was found that support by the CFHN in liaising with drug and alcohol case managers, child protection and other agencies, was particularly important for women as they worked towards keeping children in their care, or their return from ‘out of home’ care arrangements (e.g. foster care). CFHNs also assisted in raising the awareness of child protection issues through case review and collaboration with drug and alcohol staff. Child protection concerns were lessened when the multidisciplinary team and child protection service had a greater understanding of the client’s concerns and needs.

We have a different philosophy to DoCS [Department of Community Services - NSW child protection service]... it helps if we got to know them and can work together. (Drug & Alcohol worker)

Education, support and professional development

Ongoing education and support for CFHNs and other clinicians providing services to clients with drug and alcohol issues were identified as being fundamental to the fulfilment of their role. Nurses providing mainstream early childhood services also require an understanding of the particular needs of these clients to respond appropriately where contact does occur. Shared care management between child and family health nurses and drug and alcohol staff was found to provide a supportive structure for professional development.

CFHNs and drug and alcohol service staff identified Clinical Supervision as a vital component of support whilst caring for women with complex histories and needs (especially with the tension regarding their surveillance/support role):

I’ve had to make reports to DoCS... I try and tell them [the mother], but I can’t always... for my safety... and I’m not sure if they’ll still see me. (CFHN)

Nurse Unit Managers also supported access to Clinical Supervision as an integral component of effective practice for staff, which would assist in the retention of experienced staff in this specialised area of nursing.

Discussion

Drug and alcohol services have traditionally focused on providing care to women in pregnancy to reduce the impact of drug use on the foetus and improve birth outcomes. Services such as the ‘Drug Use in Pregnancy Service’ or ‘Chemical Use in Pregnancy Service’ have commenced internationally as a result of the research linking substance misuse in pregnancy with poorer outcomes for the woman and her infant (Pennock 2007, Lall 2008). Infants are carefully monitored and treated for Neonatal Abstinence Syndrome in the immediate postnatal period however less attention has been paid to ongoing care and parenting support and interventions, such as the ‘Parents Under Pressure’ program (Dawe & Hammet 2007).

In Australia, the role and scope of practice of CFHNs has developed over time and nurses are well placed to provide holistic early childhood and parenting support to all families, including those affected by substance misuse. Briggs (2007) notes the transition away from a traditional screening and surveillance model to a practice model that focuses more on psychological support for parents and addressing the family’s social needs. Families where one or both parents are receiving treatment for opioid dependence often have co-existing vulnerabilities such as poverty, domestic violence and mental health issues which add a complexity to adjusting to parenthood. CFHNs can play an important role in providing specialised early childhood support to women attending opioid treatment clinics and promoting the optimal health and well-being of the developing infant.

However, several barriers impact on the use of mainstream child and family health nursing services by women with a history of substance misuse (Battu et al. 2006). Negative attitudes of staff towards women who are receiving opioid treatment, the stigma of being labelled as a ‘bad parent’ and access difficulties (Nichols & Sword 2005, Dowdell et al. 2007, Foster et al. 2007) limit engagement of this cohort with services. Access difficulties include the limited availability of public transport to attend early childhood health clinics (Kalmanbach 2009) and the time needed to attend an opioid treatment clinic daily for pharmacotherapy, as well as attend other appointments (e.g. those arranged by child protection services) while trying to maintain a ‘normal’ life with a new baby.

Home visits and attendance at an early childhood health clinic have the potential to cause anxiety and a guarded response by women if trust hasn’t been established and the
role of the nurse is thought to be one of ‘surveillance’ (and its unknown implications) rather than one of support (Peckover 2002, Barlow et al. 2005, Jack et al. 2005, Marcellus 2005). The meaning of surveillance varies according to the context where it is being used and in this instance includes assessment of risk to an infant. Meanings range from ‘watching and observing’ (Wilson 2001) to the much stronger ‘policing’ (Peckover 2002) and may imply a ‘disciplinary power’ of the nurse (Peckover 2002, Wilson 2003). All health staff has a mandatory reporting role for child protection concerns including drug and alcohol staff. The effect of interpreting surveillance as merely observation and monitoring belies the underlying mandatory reporting and child protection role of health professionals. Small studies of women with complex needs reveal that nurses experience a tension between developing trust and providing support alongside the surveillance aspect of their role (Peckover 2002, Barlow et al. 2005, Jack et al. 2005, Marcellus 2005). Adding to the tension for nurses is that they are likely to become the object of ‘intense scrutiny’ if a child dies (Crisp & Later 2004).

The review and literature draw attention to implications for CFHN practice and the provision of early childhood and parenting support to clients of opioid treatment services. First, overcoming fear experienced by women and the development of trust are central to the acceptance of services by vulnerable families. The literature supports the view that antenatal contact with women with complex needs promotes the development of a trusting relationship which is more likely to extend into the postnatal period (Patterson et al. 2003, Barlow et al. 2005, Kemp et al. 2006, Fraser et al. 2007).

The qualities and skills of individual clinicians are also a key factor in whether or not the woman will ‘risk’ engaging with early childhood and other services. It is known that qualities of the nurse such as empathy, flexibility, openness and honesty (Normandale 2003, Davis et al. 2002, Marcellus 2005, Briggs 2007, Schmied et al. 2008) have been judged as important criteria in the development of a trusting relationship which is more likely to extend into the postnatal period (Kemp & Allison 2001) and the good intentions of the individual nurse (Jack et al. 2005) are central to the process and can influence the level of trust and the rate at which engagement occurs. The underlying model of working in partnership with families, rather than as the ‘expert’, has assisted nurses in responding to the concerns of families rather than problems identified by the nurse (Davis et al. 2002).

Despite challenges in initiating and maintaining a relationship with families who may not have otherwise sought the support of a child and family health nurse, the literature provides evidence that families with complex needs may respond positively to developing a trusting relationship with the nurse. For example, in a randomised controlled trial of mothers using illicit drugs undertaken by Bruton et al. (2006), there was little benefit following the actual intervention (support for breastfeeding), however the high retention rates in both the control group (86%) and the intervention group (93%) was attributed to the rapport that had commenced antenatally and developed between the women and the researchers over a time frame of six months. Patterson et al. (2003) and Dowdell et al. (2007) also describe the challenges of working with women with drug and alcohol issues and identify that it takes time to build the relationship. However, once trust is established, families with complex needs, as well as ‘low risk’ families (Janson et al. 2001, Russell & Drennan 2007) are able to work in partnership with nurses, particularly if there is a clear goal in mind.

CFHNs are an integral part of a multidisciplinary team providing care to children who are carers of infants and young children. Inclusion in the multidisciplinary team provides the opportunity for advocacy for the infant/child and for a greater understanding of all the factors impacting on the woman's care, continuation in treatment and capacity to parent. Observation of children accompanying their parents for opioid treatment is noted in the 'Clinical Guidelines for methadone and buprenorphine treatment of opioid dependence' (NSW Health 2006) in the context of dispensers being contacted by subscribers when a decision is being made for the woman to receive 'take away' doses (in consideration of the safety of the children). However, building a trusting relationship between women and child and family health nurses during the dispensing of opioid treatment is not evident in the literature and requires further exploration.

Increased collaboration between health, child protection and other services improves holistic care provided to families most in need of support. The maternal infant with a history of substance misuse is known and researched (Papoose Society Update - Substance Misuse 2009) even though there may be increased risk of harms to infants of parents requiring support for management of their drug use. Importantly, collaborations between child protection agencies and other government services seeks to reduce the incidence of infant mortality and morbidity ('Keep Them Safe Policy' NSW Health 2009). Rodrigues and des Rivieres-Rignon (2007) identified that women and professionals value an interdisciplinary approach with the challenge being the determination of how that works in practice. They also identified that services should be flexible and adapted to the needs of the client, rather than the historical autonomous practice of service providers operating independently of each other with a resultant...
‘fragmentation of care giving’ (Rodrigues & des Rivières-Pigeon 2007).

Specific mention of collaboration between child and family health and drug and alcohol services is limited. Published narratives of women with substance use issues describe the motivating presence of children in the women’s recovery in integrated programs (Sword et al. 2010), however gaps exist in knowledge regarding best practice in also providing services for the children. Further research is required into the impact on children attending opioid treatment services for care rather than health services focusing on the needs of children and families.

Relevance to clinical practice

The provision of early childhood and parenting services on site, as part of a multidisciplinary ‘one stop shop’ approach to service delivery was a clear recommendation of the review and in line with current international evidence. Reduction of access difficulties to early childhood support is of benefit to clients and community health services attempting to provide a service to this difficult to reach population, as well as to drug and alcohol services seeking to provide a high level of holistic care for their clients. The outcome of the review are limited to an AHS in NSW, Australia and while they are not directly generalisable to other health services, insights is provided into components of a model of care that could be applied to other settings.

Partnerships, between child and family health nursing services, drug and alcohol services, non-government support agencies and child protection services should be further developed internationally to support parents in the crucial early years of child development. Research on the effective provision of support for families with a history of substance use in the perinatal and early childhood period is limited (Dowdell et al. 2007) and the AHS review has provided a significant contribution to this important area of health. Further research is required from the perspective of women attending opioid treatment services in the perinatal and early childhood periods and to better understand the long-term impact on children and how to best serve their interests as well as the needs of their parents.

Acknowledgements

Acknowledgement is given to the health professionals who participated in the AHS review, to the Steering Committee and to the Director of the Drug & Alcohol Network of the AHS for his instigation of the review and focus on integrated client-centred care. The opportunity for endorsement of the first author to the undertake the review was supported and encouraged by the Director of the Primary Care & Community Health Network of the AHS.

Contributions

Study design: SH; data collection and analysis: SH, VS, HD, DN and manuscript preparation: SH, VS, HD, DN.

Conflict of interest

There are no conflicts of interest to declare.

References


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Appendix 2

POSTER TO ADVERTISE STUDY
Research study title: Listening to the stories of women attending Methadone Clinics regarding their experience of receiving support from services during pregnancy and after the baby’s birth.

TELL YOUR STORY!

Are you pregnant or have had a baby recently?

If yes, you are invited to participate in a small research study that aims to listen to your experience of the health care you received during pregnancy and after the birth of your baby. The study hopes to contribute to improving the care provided to women who have a new baby and attend a Methadone Clinic.

Want to know more...or participate in the study?

Contact Sue on: 0437 036 754 (If ringing on a mobile, Sue will call you back)
9881 8650 (Doonside Community Health Centre)

Give permission for Sue to contact you
(Talk to the staff at the Methadone Clinic about how to do this)

Ask the staff at the Methadone Clinic for an information leaflet which contains more details.

About the researcher:

The study is being conducted by Sue Harvey, a research student from the University of Western Sydney (UWS) with support from UWS and Sydney West Area Health Service (SWAHS). Sue is employed by SWAHS as a Child and Family Health Nurse.

University of Western Sydney

SYDNEY WEST AREA HEALTH SERVICE

NSW HEALTH

This study has been approved by the Sydney West Area Health Service Human Research Ethics Committee (Nepean Campus) and the University of Western Sydney Ethics Committee.
Appendix 3

STUDY BROCHURE
Research study title: Listening to the stories of women attending Methadone Clinics regarding their experience of receiving support from services during pregnancy & after the baby’s birth.

TELL YOUR STORY!

...if you

- Receive/d a antenatal care at a hospital in Sydney West Area Health Service;
- Will/did receive a first home visit by a Child & Family Health Nurse (offered to all women after the birth of their baby) in the next 6 months;
- Attend a Methadone Clinic run by Sydney West Area Health Service (treatment with Methadone or Buprenorphine); and
- Are over 18 years of age

Do you have a choice?

Participation in this study is voluntary. You can withdraw from the study at any time.

What is the purpose of the study?

- To gain a greater understanding of what it is like to have a new baby, attend a Methadone Clinic, & have a number of people providing care at this time.
- To investigate factors that help or hinder your contact with health & other services during pregnancy & in the first year of your baby’s life.
- The study ultimately aims to contribute to improving services provided to women & families.

What will happen on the study?

- A discussion with the student researcher (Sue Harvey) on two separate occasions at the Methadone clinic:
  1. Following the first home visit by a Child & Family Health Nurse; and
  2. Approximately 3-4 months after the first meeting with the researcher.
- You will be asked some broad questions about the support you’ve received from services, which will allow you to discuss the things that are most important to you.
- The sessions will take 45 min – 1 hour, & you are welcome to have your baby with you. With your permission, the sessions will be audio-taped.
Are there any risks?
- A possibility of psychological discomfort or distress when relating the story of your experience to the researcher. If you experience any distress or discomfort, you will be offered follow-up support/counselling through the Methadone Clinic.

Are there any benefits?
- It is hoped the study will make a contribution to improving the care provided to women with a new baby who attend Methadone Clinics.
- A personal benefit may be obtained from telling your story to someone who will listen in a respectful & non-judgemental manner.

Confidentiality/Privacy
- Use of a separate room at the Methadone clinic for each session.
- Identifiable information that is collected about you in connection with this study will remain confidential.

Cost?
- No cost to participant in the study.

Want to know more or participate in the study?

Contact Sue on: 0437 036 754
(fringing on a mobile, Sue will call you back)

9881 8650
(Doonide Community Health Centre)

Give Sue permission to contact you – sign the ‘Consent to Approach’ form provided by staff at the Methadone Clinic.

Researchers:
Sue Harvey is a research student at the University of Western Sydney (UWS), & is employed by Sydney West Area Health Service (SWAHS) as a Child & Family Health Nurse. Support & guidance for the study is provided by:

UWS - Associate Professor, Dr Virginia Schmied, Associate Professor, Dr Hannah Dahlen & Dr Daniel Nichols.

SWAHS, Drug & Alcohol Network - Mr Tim Trevor Jones, Ms Cathy Addison Wilson, Mr Grant Karte & Ms Josephine Mercigiar.

This study has been approved by the Sydney West Area Health Service Human Research Ethics Committee (Nepean Campus) & the University of Western Sydney Ethics Committee.
Appendix 4

FLOWCHART FOR PROVIDING INFORMATION TO POSSIBLE STUDY PARTICIPANTS
FLOWCHART FOR PROVIDING INFORMATION TO POSSIBLE PARTICIPANTS

1. Woman directed to the poster

2. Interested in receiving more information about the study

3. Woman provided with the colour information brochure

4. Woman indicates further interest

5. Woman is provided with the SWAHS Participant Information Sheet and Consent, and informed of the contact details of the researcher on the back of the colour brochure and Participant Information Sheet

6. The woman is requested to sign the ‘Consent to Approach’ Form (counter-signed by staff member) to allow the researcher to contact the woman and be informed of their current contact details

7. Woman unsure if she wants further information at this time

8. Clinic staff inform the woman of the contact details of the researcher on the back of the colour brochure

9. The researcher can be contacted by the woman for further information and to explore her participation in the study

STUDY CRITERIA

- Receive/d antenatal care at a hospital in SWAHS
- Will/did receive a first home visit by a Child & Family Health Nurse in the next 6 months (offered to all women after the birth of their baby)
- Attend a Methadone Clinic run by SWAHS (treatment with Methadone or Buprenorphine)
- Are over 18 years of age
Appendix 5

PARTICIPANT INFORMATION SHEET & CONSENT FORM

CONSENT TO APPROACH FORM
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

**Study Title:** Listening to the stories of women attending Methadone Clinics regarding their experience of receiving support from services during pregnancy and after the baby's birth

**Investigators:** Susan (Sue) Harvey, student researcher
- Associate Professor, Dr Virginia Schmied – Principal Supervisor, UWS
- Associate Professor, Dr Hannah Dahlen – Supervisor, UWS
- Senior Lecturer, Dr Daniel Nicholls – Supervisor, UWS
- Mr Tim Trevor-Jones - Nurse Unit Manager, Woodlands Methadone Clinic, Katoomba, and Lithgow Methadone Clinic, Lithgow
- Ms Cathy Addison-Wilson - Nurse Unit Manager, Gateway Methadone Clinic, Penrith
- Ms Josephine Mencigar - Nurse Unit Manager, Fleet St Methadone Clinic, Cumberland

**Department:** Drug and Alcohol Network,
Sydney West Area Health Service

**Invitation**

You are invited to participate in a research study into your experience of the health services you received in hospital when you were pregnant, and community health services you received after the birth of your baby (eg. a home visit by a child and family health nurse).

The study is being conducted by Sue Harvey, a part-time student researcher from the University of Western Sydney (UWS). Sue also has full-time employment with Sydney West Area Health Service as a Child and Family Health Clinical Nurse Consultant

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.
What is the purpose of the study?
The purpose of the study is to investigate factors that help or hinder your contact with health and other services during pregnancy and in the first year of your baby’s life.

By listening to your story, it is hoped that nurses and other professionals will gain a greater understanding of what it is like to have a new baby, attend a Methadone Clinic, and have a number of people providing care at this time. Ultimately, the study hopes to contribute to improving services provided to women with a new baby attending a Methadone Clinic.

Who will be invited to enter the study?
You are eligible to participate in this study of 6-10 participants because you:

- Receive/d antenatal care at a hospital in Sydney West Area Health Service;
- Will/did receive a home visit by a Child and Family Health Nurse (offered to all women after the birth of their baby) or will/did have other contact with a child & family health nurse;
- Attend a Methadone Clinic run by Sydney West Area Health Service (treatment with Methadone or Buprenorphine) ; and
- Are over 18 years of age

Do you have a choice?
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

What will happen on the study?
If you agree to participate in this study, you will be asked to sign the Participant Consent Form after discussing any questions you might have with the student researcher (Sue Harvey) and/or others listed on this information sheet.

The study will be conducted over 4-6 months, and this is planned to include a discussion with the researcher on two separate occasions:

1. Following the home visit by a Child and Family Health Nurse; and
2. Approximately 3-4 months after the first meeting with the researcher

To ensure privacy, a separate room will be provided at the Methadone Clinic for you to speak with the researcher, at a time that is convenient to you. The sessions will involve you being asked some broad questions (including questions about the support you’ve received from services) and will allow you to discuss the things that are most important to you.
The sessions will take 45 min – 1 hour, and you are welcome to have your baby with you. With your permission the sessions will be audio-taped to allow accurate review of the discussion.

Please note:

- If you are still pregnant at the time you consent to participate in the study the student researcher (Sue Harvey) will contact you after the expected date of delivery of your baby. Sue will ask how things went with the birth, and whether or not your baby is home with you.

- If your baby was born early (and has come home from hospital) you are asked to inform the student researcher so that an earlier session can be organized.

- If your baby needs prolonged additional care in hospital, or is not in your care after you come home from hospital, you will be given the option of continuing to meet with the student researcher or withdrawing from the study.

Are there any risks?
The known risk of this study is the possibility of psychological discomfort or distress when relating the story of your experience to the researcher.

The potential severity and duration of the discomfort or distress is unknown, and may be minor. If you experience any distress or discomfort, you will be offered follow-up support/counselling through the Methadone Clinic.

Are there any benefits?
While the study may not directly benefit you, it is hoped the study will

- Contribute to improving the way nurses and other health professionals care for women who have a new baby and attend Methadone Clinics

A personal benefit may be obtained through taking the opportunity to share your experience and story with someone who will listen in a respectful and non-judgemental manner.

Confidentiality / Privacy
Of the people treating you, only those named above or necessary others eg staff at the Methadone Clinic who gave you the information about the study, will know whether or not you are participating in this study. Only the researchers, Sue Harvey and Associate Professor Virginia Schmied will have access to your details and results that will be held securely at the University of Western Sydney.

If you give permission for the session with the researcher to be audio-taped, the tape will only be identified by the date of the session and a number code. All data will be stored in a password-protected computer and a locked filing cabinet (with a separate list of the code and details stored in another password-protected computer and locked filing cabinet).
Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law.

**Will taking part in this study cost me anything, and will I be paid?**
Participation in this study will not cost you anything.

In recognition of your time, a Coles Gift Voucher will be provided after each interview with the researcher (voucher to the value of $20).

**What happens with the results?**
If you give us your permission by signing the consent form, we plan to inform nurses and other health professionals by publishing the results in peer-reviewed journals and present the results at conferences or other gatherings of professionals. There will be no way to identify you personally in any written or verbal presentation of the study results.

A summary of the findings of the research will be provided to you if you wish.

**Complaints**
This study has been approved by Sydney West Area Health Service Human Research Ethics Committee (Nepean Campus). Any person with concerns or complaints about the conduct of this study should contact [name of patient representative and hospital name] who is the person nominated to receive complaints from research participants. You should contact them on [number] and quote [HREC project number].

**Contact details**
When you have read this information, the researcher Sue Harvey will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact Sue.

**Mobile:** 0437 036 754.  
**Phone:** 9881 8650 (Doonside Community Health Centre)

**Working hours:** 8.30am – 5pm; Monday – Friday

Please note: If you contact Sue using a mobile phone, Sue will call you back to limit the cost of the call.

Alternatively, Sue will contact you direct, if you complete the ‘Consent to Approach’ Form (available from staff at the Methadone Clinic).

**Thank you for taking the time to consider participation in this study.**

**If you wish to take part in it, please sign the attached consent form. This information sheet is for you to keep.**
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Study Title: Listening to the stories of women attending Methadone clinics regarding their experience receiving support from services during pregnancy and after the baby’s birth.

Name of Researcher: Susan (Sue) Harvey

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.

2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by ____________________________ (“the researcher”) and I, being over the age of 18 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.

3. I acknowledge that I have been given time to consider the information and to seek other advice.

4. I acknowledge that refusal to take part in this study will not affect the usual treatment of my condition.

5. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.

6. I consent to the audio-taping of sessions with the researcher

7. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.

8. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.

9. I acknowledge that any regulatory authorities may have access to my medical records to monitor the research in which I am agreeing to participate. However, I understand my identity will not be disclosed to anyone else or in publications or presentations.

Name of participant _______________________________ Date of Birth ______________

Address of participant

____________________________________________________________________
Signature of participant ___________________________ Date: ___________ 

Signature of researcher ______________________________ Date: ___________ 

Signature of witness _________________________________ Date: ___________
CONSENT TO APPROACH

I give my permission for my name and contact details to be given to the researcher, Sue Harvey and for Sue to contact me. I understand that I am not obliged to participate in this study.

My name is: ___________________________ (please print)

Signature: ___________________________ Date: ________________

My telephone contact numbers are: (Home) _______________________

(Mobile) ______________________

The best days/times to call me are: ___________________________

I also give permission for the staff of the Methadone Clinic to provide the researcher, Sue Harvey, with my new telephone contact details if I can no longer be contacted on the above telephone numbers.

Name: _______________________________________

Signature: ________________________________ Date: _____________

Name of witnessing clinician: ___________________________ (please print)

Signature: ________________________________ Date: _____________

Study Title: Listening to the stories of women attending Methadone Clinics regarding their experience of receiving support from services during pregnancy and after the baby's birth

Researchers: Sue Harvey, student researcher
Associate Professor, Dr Virginia Schmied
University of Western Sydney
Appendix 6

‘LISA’S STORY’

‘I’ve learnt to ask questions if there is something I don’t know’
I've just had my 5th child a couple of months ago – Ben, he’s lovely. As well as being a new mum, I’m also a grandmother and have two grandchildren. I was 15 when I had my first baby, and the next two came along pretty quickly after that. Then there was a ten year gap before I had Will. He died from SIDS when he was 3 months and 10 days old so Ben came home from hospital on a sleep apnoea monitor.

Housing has been an ongoing challenge – I’m homeless at the moment, just in the temporary accommodation that Dept of Housing organise each week. When I came home from hospital, I had organised to stay at a friend’s house and split the rent and everything, but that didn’t work out. He got the police to move me out after I complained that I’d found a syringe on the floor and other gear around. He was on the programme and I thought it would be alright, but he started using again. I was so worried that it wasn’t safe for Ben – the syringe could have dropped into his pram, or he could have rolled onto it on the floor – and what would happen if DoCS walked in the door and found stuff around! I just couldn’t risk him getting hurt or DoCS thinking that I wasn’t looking after him properly, and taking him off me.

I also missed dosing yesterday because I had to take Ben for an ultrasound because his scrotum swelled up and was all red - it turned out that he needed antibiotics. So getting all that fixed up, as well as trying to sort out my housing didn’t leave enough time to come in. I actually want to talk with my DoCS worker because I’m not sure if where the Dept of Housing find me accommodation will be OK. Should I be turning it down if it’s a hotel at a pub? I don’t want to risk losing him.

A far as being pregnant and having Ben goes, things went pretty well even though I had my first Caesarean. It wasn’t what I expected, and it was scary because my blood pressure dropped, but it was pretty much OK. I was worried what would happen when I went into hospital because I’d smoked a bit of pot in my pregnancy and I’d heard stories that DoCS might take the baby after he was born. I was on the methadone program when I was pregnant with Will, but they weren’t involved so I wasn’t sure what they’d do this time.

Everything was fine until one of the nurses in the Special Care Nursery put in a report about me. I knew nothing about it at the time, and it wasn’t until I was just
about to go home that DoCS called a meeting. The social worker came to find me, and when she told me I was just terrified that DoCS were going to take him. It turned out that the report was made because I was falling asleep! I was tired, but I put him back in the crib and was just resting my head on the top. None of the ladies sitting there and falling asleep with babies in their arms had to have meetings with DoCS, so I felt a bit discriminated against. I was so relieved that they just assigned me a case worker and I could go home with Ben if I agreed to do all the things they wanted me to do.

Other than the nurse who made the report, it was overall pretty good in hospital. The breastfeeding lady was really good – she helped me get going with feeding and had been talking with Diane about some education for the nurses. A lot of them don’t even realise that methadone’s ingested, not injected so they need more information. Even though some nurses might not approve they’d treat you how you treat them, so it was pretty fair. All except that one younger nurse who I just think needed some more education about methadone and how the program works.

I had two visits by a child and family health nurse when I went home from hospital. They were only a day or so after I’d seen Dr Smith and Diane at the Methadone Clinic. If I hadn’t been coming in to see them it would have been wonderful, but I had to come in anyway because Ben was on morphine and needed to see the doctor. The visits at home were pretty much as I expected, as I’d had other home visits when Will was born. I’d gone to the baby clinic with him too, but this time I’ve just been coming here because I can have a chat to Diane about how Ben’s going. Dr Smith and Diane have been great. Dr Smith arranged a sleep apnoea monitor for when I went home from hospital and sleep studies because Will passed away from SIDS. Ben was really unsettled and they both listened to me and got some tests organised. I thought that they’d think that I had the Munschausen Syndrome and made it all up because he was quiet when they saw him. It turned out that he had reflux, and he’s much better now with some medication and different formula.

My DoCS worker is also lovely, and she and her boss are fine. It’s just hard to fit everything in when you’ve got a newborn and you need to come in for dosing, meetings and urine collections. I haven’t even had time to take photos of Ben since I came home from hospital. At least I don’t have to do the urine collections at the pathology place anymore – they stand in the room and watch you – it was really horrid. I should be finished with all that in a month if everything is OK. DoCS are
looking at changing me over to Brighter Futures for extra support without the child protection part. I just want to make sure that I'm doing all the right things so they can't just come in and take him, so that's fine – we'll get there.

I've learnt to ask questions if there is something I don't know. If they don't know, they can ask someone else and find out. There are lots of services out there if you need them. You have to not worry that people might think it's a stupid question – just ask. At the moment I'm trying to decide whether or not to keep coming here for dosing or to try and get dosed at a pharmacy. Somewhere closer because now it is winter I'm worried that Ben will get sick if I'm bringing him out in the cold. I also just want to spend more time with him – having a whole day at home to enjoy him instead of having to rush out. But I don't want to stop coming here either because I still want to be monitored.
Appendix 7

‘EMMA’S STORY’

‘It has helped me a lot to be treated with respect’
I was 8 weeks pregnant when I had an ultrasound and found out that I was going to have my first baby. I was nearly off methadone before I became pregnant, and I want to get off it as quickly as I can – I don’t want to be on it forever, especially with a baby to look after. When I was pregnant lots of people coming to the methadone clinic were telling me to watch out for DoCS. I got really upset because I thought that DoCS was going to be involved straight away. At the antenatal clinic they had to ask all these questions about my history. It was a bit intimidating but it wasn’t so bad because I was asked all those sort of things when I was on the MERIT program. It’s a bit more intimidating though, when you’re going to have a baby and it’s all about her, so I started to stress and worry a bit.

I was also really worried about what it would be like in hospital, because of what I’d been told. I got told about people’s bad experiences, where the midwives would yell out ‘Oh, your methadone’s here’ in the ward and things like that, but that didn’t happen to me. Maybe those women went to a different hospital, because everyone was really discreet about it. They also showed me stuff and I didn’t feel worried about asking them about anything and didn’t feel like I was hopeless for asking.

The only thing that was a bit of a problem was when I was in labour. I knew the baby was coming, but they didn’t believe me. They said it might be another 2 or 3 days because I was only 1 cm dilated when I came into hospital. My partner told them that my contractions were getting really close, but they thought they were 10 minutes apart. I had an internal and then they took me seriously – practically ran me downstairs to the birth unit! I had an epidural even though I decided after going to the parenting class not to have one because the gas just wasn’t enough – I’m having one or I can’t do it. But otherwise it was alright.

It was great that Lizzie didn’t need to be in the Special Care Nursery for long, as she didn’t withdraw. The nurses were scoring her high because she was unsettled, but when she was on the bili-bed she was better, so she didn’t need any morphine. She was perfect – just had a little bit of jaundice. I was in hospital for seven days. Everyone was really good to me and to her; they didn’t seem to get sick of me. I felt that I could ask any questions without being scared and I had no complaints. I think that if they had been rude to me, like people told me to expect, I would have felt worried to ask about things. I probably would have just been out of there and made some excuse to leave if they were rude. But they weren’t like that at all and I’m
grateful for that – the nurses were really great, so I stayed the seven days, which was a long time. I bought them a thank you card and everything.

It was really good to go home with my baby. My mum helps me a lot and I’d got all the baby stuff organised, which mum unpacked before I came home from hospital. After I got home I had a phone call from a child and family health nurse to ask if they could come and do a home visit. She wanted to come that day, but it wasn’t going to work out because I was already going to see Dr Smith. So I had the home visit a couple of days later. The nurse was really nice and I knew that she was there to make sure that Lizzie was OK.

It was fine having the nurse come to my home, but she explained that there wasn’t much point her coming because I’m already seen by Diane and Dr Smith. She saw how I had everything set up like the baby’s bath and change table, because it’s all in the lounge room. I think that she realised that everything was there that needed to be. I thought that she’d come into my room and see where I’ve got the cot, but she gave me the SIDS pamphlets. I also got a calendar with info about the baby’s development and she checked to make sure Lizzie was gaining weight. She covered all the bases – made sure that I was getting seen for all the right things and wanted to know if I’d seen anyone from DoCS, but I said no. The nurse asked me if I wanted to see her at an early childhood clinic, but it’s easier for me to go to see Diane because I go to the methadone clinic every day anyway. She said that we’re wasting each other’s time if you’re already going there, which I thought was fair enough. I respected that the nurse didn’t just rave on for no reason. She said that if I needed anything or if I did stop going to the methadone clinic and seeing Diane about baby stuff, that I could contact them and they’d come and see me or I could go to a clinic.

I also got Lizzie checked out by my GP when I came home from hospital because they gave me a letter for her. She weighed her and did everything as well and I’ll probably keep taking Lizzie there, even though when I go I might see a lot of old ‘friends’ that I’ve known from before. I don’t want them hanging over my baby and touching her because she’s got no immune system. They might think I’m rude if I ask them to use that antibacterial hand stuff, so I’m trying to stay away from them. I don’t really want to change doctors and go somewhere else because my doctor knows my history and doesn’t treat me any differently. I thought she would,
because some of them are a bit weird and go a bit funny when they know, but she's really good.

They're also really good at the baby clinic at the Methadone clinic – they're really friendly, they're good with Lizzie and they know what they're doing. If I ask something, I don't have to explain it further because they know straight away. I know that Lizzie’s safe and they’re doing the right thing, and that’s important to me. I've never felt uncomfortable because Diane and Dr Smith have been really nice and they've made me feel comfortable. The only thing is that I'm going to be off the methadone soon. Dr Smith said that I can still come in here for Lizzie’s first immunisation but then I will probably need to look at my options. I can perfectly understand that because there’s other girls having their babies too and if I don’t have to come here then it’s probably better that I don’t.

Becoming a mother is the best thing that’s happened to me. I always wanted to be a mum, but I didn't think that I would be, so it’s fantastic. I knew what to expect because I've got so many brothers and sisters. I don’t want to leave her with anyone, even though I left her with mum and ran down to the methadone clinic for my dosing the other day – it was just too hot to take Lizzie out. I won't ever leave her with my brother and his girlfriend though because they had their two children taken by DoCS. I'm a bit worried how DoCS would see that and also if they're not allowed to look after their own children, I don’t want to risk leaving Lizzie with them.

It will be good to be off the methadone. I’m nearly half way there, and I’ve been feeling alright, I just sweat a lot on my face until about the fourth day of the dose coming down. I didn’t get off it the proper way before, just jumped off when I was on 100mls. I was sick for about 4 or 5 months and I swore that I’d never go back on it, but I got back on drugs with the wrong boyfriend. I’m a bit worried about how I’ll go when I finally get off the methadone, but I’ve got a baby now and I’m not going to get in with the wrong crowd and go back to the drugs.

It has helped me a lot to be treated with respect, and not looked down on. When that happens I feel like I’m a normal person and not like I’m on methadone. Other people might have been treated like crap, but maybe they had a bad attitude or something too. I don’t know. I just know that I’m having treatment to get help. People should know that I’m not on the methadone program because I want to get
drugs. I still feel broken by my past and need some more healing. This is a step in the right direction.
Appendix 8

‘JOANNE’S STORY’

‘it was a relief that I wasn’t being watched over anymore’
I had my first baby when I was seventeen and it was really hard; he’s thirteen now. I’ve had five children, but I’m only looking after the last two. DoCS took the older ones and mum’s got them because my drug use meant that I couldn’t look after them properly. The youngest one, Tom, is nine months old and my daughter, Michelle is two years old. They live with me and Tom’s dad, and my older boys live around the corner with my mum. I want to get them back.

I found out that I was pregnant with Tom at around 8 weeks. I changed Methadone clinics so I could go to the same hospital where I had my first three. It’s a bit uncomfortable being asked all those questions at booking in, but I got used to it after having the other kids. With my second baby, I didn’t tell them everything I was using, because I was worried that DoCS would take him from me because they’d been involved before. I didn’t know the effect it would have on him. But I had to tell them because he started fitting when I was leaving the hospital to go home. I had to take him back to the ward. He was really, really sick because I was lying. I was scared that he might die – it gave me a real shock, I was just so upset. My mum was really angry with me for lying the whole time about taking stuff. She knew that I was on something, as mum always does.

I was thinking I’d lost him when they told me that DoCS wanted to see me. He was in hospital for quite a long time after he was born and then stayed on the morphine for months and months. I thought that’s it, I’ve lost him, they’re going to take him. They said the only way I was going to leave the hospital with him was if I went on the methadone program. I think it’s easier to get off street methadone so I didn’t really want to do it. Although it was my choice, I still feel angry with them; angry that I’m on methadone. But I was using already, so I was the one who put the needle in my arm. That was the choice I had to make. If I hadn’t chosen, they would have taken him.

This time, I was the one who noticed the withdrawals start in my son. The first night was excellent, Tom slept right through, but then he wouldn’t take to the breast properly, he was sneezing all the time and kept jumping or having little tremors. It was really getting to me, and I was crying and feeling depressed. One of the midwives heard me crying and came and sat with me to calm me down. She asked how I was and we had a good talk. We did a score chart and she explained that the score was really low but that it might be higher the next day. I was sort of expecting
that anyway. I guess I was just hoping that he wouldn’t go through withdrawal and it would be different this time. By the next day he was in full withdrawal.

I was really happy with the NICU because they were excellent; they got him in straight away. As soon as he had high scores they put him straight on the morphine and they treated me really well. I didn’t feel discriminated against because Tom was going through withdrawal. They were really nice and didn't look at me as if to say ‘you’re a drug addict’. I was supposed to stay in for seven days, but they said there were no beds on the postnatal ward for the last two days and I’d have to leave. The NICU did their best for me to stay, and so did the drug and alcohol team and Diane, but they just ignored it even though I saw plenty of empty beds when I went up there. I didn’t want to leave Tom and NICU ended up putting me up beside his cot, beside the sink; that was the only room they had. I was just so grateful, because I could wake up and see what was happening to him. In the hospital, the ladies in NICU are the best.

Before Tom went to NICU I felt like I was treated differently by some staff on the postnatal ward. I was told different things about what to do if I wanted to leave Tom for any reason which made it confusing and it seemed like I was doing the wrong thing. Like I was told to ask the midwife to watch the baby if I was leaving him to go to the cafeteria, have a smoke or have a shower. Then when I did that one of them had a go at me and was really rude, saying staff are not there to be baby-sitters. So it seemed a bit strange when I’d go past the desk and the same midwife would be there with an African baby. I don’t know if she was racist or judgemental, but she seemed racist because she wouldn’t touch white babies. I always felt eyes on me and I felt really small, belittled when they’d just come up to me and tell me I was doing something wrong especially when it was in front of other people. But that midwife who talked with me when Tom was withdrawing and I was so worried and upset, she was excellent. She was really soft with me and which helped because I think I was starting to go through depression.

After I left hospital, I had appointments with Dr Smith because Tom was on the morphine and needed to be checked out every week. I also had a phone call about a nurse coming to visit me at home. They said that they would get back to me and they would come around, but it probably would be a couple of weeks. The only problem was it never happened and I didn’t have a number to ring them back. I was disappointed because I’d had a home visit with some of the others. It made me feel
safer and more content because I had a newborn at home. It was good when the
nurse came and did the check and said that the baby was fine.

At least I can ask questions when I come to see Dr Smith and Diane (child and
family health nurse at the methadone clinic). They answer my questions properly,
treat me well, and don’t discriminate or judge me because my baby was going
through withdrawals. I guess it’s because they see it every day and because they
aren’t that type of people; they’re understanding and they love their job. If people are
judgemental, I’ll go somewhere else. It used to make me angry that I was being
judged, and I was a bit mouthy. Now I can sort of blow it off because I know that I’m
not doing anything wrong, but in a way it still makes me feel angry. I wonder how
some people here are allowed to have their kids, and that makes me angry,
because I’m doing the right thing.

I’ve known Diane for a long time, from when I was young and first started coming
here for methadone. Diane’s known me from when I was really bad and I had all
missing teeth and I looked shocking, like 20 years older than what I was. She’s
noticed a big improvement in me. I haven’t really been to other places to see a
nurse for help with my children – it’s hard when I’ve got to go in for my methadone
each day. I also saw a child and family health nurse a couple of times at the other
methadone clinic, but because I had to hang around the clinic even longer to see
her, I thought that I’d go somewhere else. But I’m thinking I’ll keep coming to see
Diane, even though I don’t need to see Dr Smith anymore. I bring both the kids here
for their needles and certain things. My partner was talking to Diane the other day
because Tom’s nine months old, but he’s not crawling yet, and we were wondering if
that is normal. He sits up well and pulls himself up, so I think he’s OK, but it’s good
to be able to ask. He had to have some physio because he kept lying with his head
on one side but not the other. One of my other boys had the same thing and it
helped having the physio.

There’s a playgroup here too, it’s really good. I think they’re excellent with the kids
and they’re not judgemental in any way. Sometimes they tell you the obvious; I have
had five kids. Maybe because I’ve lost some, they feel like they need to tell me what
to do with the kids. Like I can take advice, but if it’s really obvious it gets on my
nerves. But they’re really nice and my daughter loves going. It helps to have
somewhere for her to go so she’s not sitting in the methadone clinic listening to all
the talk about using drugs and drinking and stuff. She doesn’t need to be around
that. The worst thing about coming to the methadone clinic with my kids is what they might hear and see. It’s bad enough having to bring them here; it’s all they know then. Things have been hectic lately because both the kids have just been in hospital with really bad asthma and now Michelle has eczema, Tom’s teething and they’ve both got colds. It’s extra hard to come in when the kids are sick.

Also, it took a lot of the day up and a lot of the week up when we came by public transport. We’ve just got a car and it only takes 15 minutes to get here now, but we use to be out nearly half the day. We’d catch a bus and a train and then walk or catch another bus if it was really hot or cold. By the time we’d get here it would be packed but it was too cold to leave earlier in winter and the kids were always getting sick. Even with the car, we still have to wait for both of us to get dosed. Frankie can’t keep a spot for me in the line when I’m waiting in the car with the kids. If we could, we wouldn’t bring them here, but it’s not an option, petrol’s too expensive for us to come separately.

Diane’s also my case manager, so she helped me get onto Brighter Futures for early intervention. She put in some recommendations when I was pregnant, so even though Brighter Futures are in the DoCS office, it’s separate and it was a relief that I wasn’t being watched over anymore. I’ve got a lot out of them, I’ve learnt a lot and they’ve helped with a lot of things like budgeting. At first it worried me, in case I slipped up, not even just on drugs. Slip up in any way, like speak wrongly in public or where it sounds like I’m abusing the kids but I’m not. I just get real wary now wherever I am. I’ve never had any involvement with DoCS with Michelle or Tom; so far, so good. I’m just a little bit worried at the moment, because I’m working towards going to court to get my three eldest boys back. My eldest one wants to come and stay at my place, but he doesn’t understand that it might affect the case if DoCS hears about it. I hate to have to tell him to go home to his Nan. He had such a hard time being abused by my ex-partner when he was little. Diane’s going to write a letter of support for the court case, so I hope that helps.
Appendix 9

‘KRISTY’S STORY’

‘they see me, they are behind me, they are helping me’
My Nan and Pop had two daughters, my mum and my aunty. I’m Mum’s only child and all I know about my dad is that he was schizophrenic or something like and that my mum apparently told the police he was involved in a murder. Nan and Pop raised me until I was 13 or 14 years old and then I went to live with my mum. I’ve got three children. I had four but Jake passed away a few years ago. There was never a real answer to what happened, and the Coroner couldn’t rule out natural causes, but I think that Jake’s dad had something to do with it because his behaviour was different and when I thought about it later, it seemed really suspicious. Jake was 4 months old at the time, and I also had Matthew who was two. I went to bed and left Jake with his father to give him a bottle; I’d never done that before.

All this happened a long time ago. I stopped talking about it after it happened and it’s taken me a long time to be able to talk about it without breaking down. Things got worse because I also lost Matthew to DoCS at the same time. I didn’t understand what was happening because it was like I was in the Twilight Zone when I went to the hospital with Jake. I thought DoCS were just taking Matthew for the night. People were saying things to me but I couldn’t take any of it in because my baby had just passed away. It turns out a social worker at the hospital put a report into DoCS because she noticed a big strawberry birth mark on the side of Matthew’s head, but she thought it was a bruise. It was only after I got some court orders that I knew it was for more than overnight. I had to say goodbye to Matthew at the hospital.

The police kept coming to my house after Jake died and wanted to talk but there was no way I was going to let them in because my partner was behind me sort of pulling the strings. It wasn’t until one day when he actually grabbed me by the throat and picked me up that I thought, wow, I think he’s done it to Jake and he’s doing it to me. There was a lot of domestic violence in my relationship with Jake’s dad. I suppose when a partner hurts you, you think okay, they are going to hurt me, they are not going to hurt anyone else, but because they are violent you don’t know if one day they might snap at your children and that’s what happened with me. I shouldn’t have had my children in that situation, but it’s only with hindsight that I get that. So I just walked away and a lady saw me and took me inside so I had somewhere safe to ring the police. I had hoped to get Matthew back, because I’d left Jake’s dad but I just wasn’t capable. They wanted me to stop smoking.
marijuana and do a couple of things, but there was a lot of grief towards Jake and I wasn’t capable. I didn’t have housing so I was living with my mother, and I wasn’t allowed to bring my son back there.

Matthew’s been living with his foster family for eight years now, and I’ve got a very unique relationship with them. It’s a good relationship where I can talk to his foster mum and there’s a lot of trust. She knows that I’m not going to take off with Matthew. It’s much better for Matthew to stay with the foster family after being there that long; it would only be if they couldn’t look after him anymore that I’d go to court to get him back. Matthew knows that he’s got two mothers he says oh Mum was young when she had me. It hasn’t been explained too much about his brother, and maybe if he starts asking I’ll just give a quick answer until he’s old enough to understand. I want to protect his childhood. I get invited to Little Athletics and get his school photos and his foster mum introduces me to people as Matthew’s mum, so people know. I try and attend all the monthly visits and every second month I stay over there; it’s really, really cool.

We’ve come a very long way. This has been eight years of DoCS; being in the DoCS office behind a window where people watch you and then McDonalds supervised visits with escorts. Had I known probably at the start that I would get to this stage I would have been a bit more relaxed maybe, knowing that sometime down the track I’d have a relationship with my son. Because when your child goes to DOCS you think, I don’t know where they are, I don’t know who they are with, and all sorts of things go through your mind. Yeah, so that’s good. I think you need time to get to know the people at DoCS, and that they’re trying to help.

When the child is with you, you want to do anything to keep them. I know, because DoCS talked to me before Liam was born and I needed to do some things because I had some mental health stuff from all I’ve been through. Then the night I came home from hospital with Liam his father committed suicide out the back of my house. He tried to take the baby off me and we had a bit of a kafuffle and he’d never been violent but he sort of tried to push me out the door. I’d had a caesarean and I was worried about my stitches sort of getting cracked and then he just went out the back. The last thing I said to him was I hate you, before he left and did everything. He was 23 years old. I was in hospital for 13 days with Jarred and I don’t know whether that played a part in his dying; me not being around.
Mental health came out every day to see me. When it first happened they gave me some sleeping tablets for that night. I must have gone to sleep and I was okay. They came out every day and they were fantastic, they follow up. They were even coming and crying with me and you know, saying I was really strong with everything I’ve been through. DoCS arranged a temporary care order for Liam with Nan as the carer but I did everything. I am very, very lucky to have my Nan and at that time I don’t know how I got through it but you just do. It was difficult with Liam because I’d be breast feeding him and I lost all my milk. I couldn’t have Liam on me because he could feel the stress, so Nan would then have to come and take him and put him to bed. So there was a while there that I suppose I didn’t bond with him because I’d just lost his father and everything like that, but lucky I had help next to me, which was fantastic and Nan has always been there for me.

I got on the Methadone programme and started seeing someone from mental health when I was in hospital with Liam because they’d found stuff in his urine. It was only a small amount though; he didn’t need any medication which was really good. So in that way I got help and I got on the programme stably and it was good for about a year. Then I had a partner who made comments about people on Methadone walking a certain way and all lining up and I didn’t want him laughing at me. So I jumped straight off the Methadone and started taking other substances, speed and stuff which is really, really bad. But a few months later when I got pregnant with Adam I just had to tell the social worker and the other workers at the hospital because there’s so much background with me. The social worker was fantastic because of the help and compassion I felt from her; she understood where I was coming from and got me straight onto the help I needed.

I find that by telling them the truth it actually helps, even though some people are scared of doing that. If I am bad towards my children or if I was hurting my children or something, I wouldn’t want to have them, you know. It’s not right for a person to put their children through that. There are plenty of good people out there that will look after your children, not that I want them to but if you want to be around doing stuff to them you are better off sending them somewhere where they are going to be loved and in a family that can give them the right things in their life. That’s a selfless way rather than if you are off your face, taking pills and doing stuff and dragging your kids around.
My mother is a drug addict and my aunty is a drug addict. Rather than giving me food or something it was giving me cones or pot. Mum thought by doing that I wouldn’t go anywhere else and smoke. Mum actually said to me the other day, I gave you all the drugs and everything, you know, I did everything for you. I said, yeah but you just weren’t a mother. Now I have children I know what’s right and wrong for my children and I dread if my son came home and had red eyes or had been smoking or something like that; I’d want to boot him up the bottom. I wouldn’t want to give it to him and say okay sit down with me and let’s condone it. Children get hooked on drugs and feel they have to go out and steal something so they have money or food or things because their parents don’t look after them. The relationship with my mum was really unhealthy. I had to take responsibility for myself at 13 or 14.

Now I’m up to the Liam and Adam part, and that is my life and this is where I like to try and stay and keep forward. Instead of like sitting back in the past where I’d be thinking about all the bad things that have happened to me, I shoot forward for the future with the kids because that’s what they need. Everything is so fun; it’s like being a child, we’re like best friends. I’ve just split up with their dad after being together for about a year and a half. He’s been on the methadone program too and has come right down to 2ml which is a very small amount. He was just going to jump off it but it’s better to sort of stay around on it; with the children we’d rather be monitored. It sounds terrible actually, like we are still coming in to get methadone but I’m afraid that if he didn’t he’d go back to something on the street and that puts the children in danger.

Nan is not far away and she is over every day. She’ll help me do anything, any washing or housework or looking after the kids while I’m getting methadone. I am just here to help, she says. I’m here to help; I’m here to do whatever you like. Sometimes at night time I think, I’ve got to wash up because Nan is coming tomorrow and she’ll wash up for me if I don’t. I think Nan and Pop blame themselves because both their daughters got into drugs. They were pretty strict, but they worked hard and even bought the girls horses but it didn’t stop the girls doing what they were going to do. My Pop is a bit of a drinker but my cousin and I were also raised by them and we were hardly ever, ever smacked. Nobody forced people to take drugs. My cousin stayed away from the whole drug scene and she’s got married and gone through university and is doing really well. So I’ve got a good
connection with someone to relate to and build a family part for my children if anything happens to Nan and Pop, rather than with my mum and aunty.

My mum wants to come over and have a relationship with me, but I'm worried about the influence she might have on my children. I see her and my aunty at the methadone clinic, because they're on the programme too. I don't know if I'm judgemental or anything but it's embarrassing; just the state of how they are and how they live. I've tried to amputate our relationship because I'm trying to be responsible for my children but she doesn't understand and thinks she can help me now even though she didn't when I was little. I'm working on lots of things with the psychologist at the clinic. I don't drink and I'm trying to contain my smoking and not to have any contact with things that have hurt me. I get angry and stressed whenever I talk to my mum and take it out on people and the kids and I don't want it to be like that. I've realised now that I just wanted my mum's love when I was little because she was on drugs and I always thought what's the matter with me, why doesn't she care about me. It wasn't me; it was her being off her face and not comprehending anything around her basically. So I have come to understand that and I have got children and they are my responsibility. I have to look after them and stop the vicious cycle. I'm their mum.

Experience of services

I've had lots of people help me along the way. Tracey's my case worker at the Methadone Clinic and she looks at a whole lot of things like whether I've got proper housing, and if I'm eating properly and my health. She asks me if I've maybe used anything and how I'm feeling – all that sort of thing and wrote a report for the hospital when I was pregnant. When I started going to the antenatal clinic I felt a bit worried that everyone would be looking at me and I wondered what the midwives thought about me when they were taking my blood pressure and doing all the checks. Maybe that's the same with everyone in the first few months of pregnancy. There was one lady who saw me in the antenatal clinic and I was a bit baffled about her job. She just took me into another office for a few minutes while I was waiting to see the midwife and asked me if everything was OK with my dose and stuff like that. I was confused because I've got Tracey at the Methadone Clinic for that. I found out later she's a drug and alcohol worker in the hospital and she can help talk to other people if I had any trouble with my dose or any problems with discrimination while I was there and she also talks to the nurses at the Methadone Clinic. She ended up
being fantastic and has an important role but it would have helped to understand what she does earlier. I probably would have told her to go away and leave me had I not been a polite person.

My dose of Methadone changed when I was pregnant. I think I was on 75ml and I went down, I went down slowly to 60ml and then back up. When you are pregnant they say your dose needs to go up because the baby absorbs a lot of it and stuff like that. I feel like they are pushing you to sort of go up a little bit with bubs when you don’t want to it to go up, because you’re feeling OK. I wasn’t really afraid because I felt assured that it was okay to go up and then he’s withdrawn a lot when he came out. Before I had the caesarean in the morning I wanted to have my dose but they said I couldn’t do that. Maybe if I did my baby would have still had some in his system because when he has first come out he, like all babies, started screaming, you know which is great, you know that they are healthy, they’re alive and everything, but later he started to withdraw, scream, like wouldn’t sleep, wouldn’t drink, wouldn’t do anything.

When I first had Adam they kept him upstairs with me, every time he would be on my chest he would go to sleep because he was comfortable listening to my heart beat but then I was going to sleep. Firstly you sit down and you start feeling tired like any other mother, but if you’re on Methadone you have to be so careful because somebody would come past and think you’re not looking after your baby properly. A nurse came and woke up the lady next to me whose baby had been crying for about 10 minutes, but I think people on Methadone get seen differently with stuff like that. I have to keep my eyes wide open and everything. Adam then had to go to the special care nursery because he was withdrawing and that was hard because I wanted to be with him. I went there and they give you a whole lot of information but I didn’t really understand it. Like why the doctors put him on a set dose and bring him down, I don’t understand why they don’t maybe give him a little bit and then see if he was hanging out before giving him a bit more. They’d be their own reasons for that but I don’t think it was ever explained to us and I was really worried that my baby would be given too much because my friend’s baby was on a lot and she went blue and cardiac arrested. It was also confusing because I was told that maybe babies wouldn’t hang out, maybe they would, like some babies whose mum’s are on 200ml sometimes don’t hang out, some babies do.
I suppose, we also feel guilty about having a baby and they come out and they are withdrawing. I tried to stop using when I was pregnant with Adam. I tried to stop and I was withdrawing really bad and it’s twice as bad because you are vomiting up with morning sickness too. So that’s when I came to hospital, I didn’t know what to do, but I knew I needed to talk to someone and try and get help. It was the best thing that I ever did but I was also worried that by doing that I may lose my children because it’s illegal for me to be using. I’m glad I did it though because they will help you.

Most people at the hospital were really good; maybe one out of ten people might have their nose up. I suppose they’re not knowledgeable enough, they just see oh Methadone, Methadone, street heroin, junkies off their face or whatever. They get the wrong opinion and don’t understand it enough and just walk past you and look at you like you’re a piece of crap or something. Some of them they don’t say anything but you can sort of tell that they judge you because you’ve had a baby who is on Methadone and you know it’s in the doctor’s notes. That’s the way that I think and I feel because I get that impression from how they look at you, but I don’t know if that’s what they really think. No-one’s actually been spiteful to me and you get some midwives that really, really help you.

One of the midwives on the postnatal ward was so non-judgemental and she really listened and helped me a lot. Like when I thought I wouldn’t be able to have any pain tablets after my Caesarean because I was on Methadone. She actually asked if I needed anything for pain and I said I didn’t want to take anything if I was going to be on the nod. So it was fantastic that she answered all my questions as a mother and knew about the Methadone as well. I actually wanted to nominate that midwife for her care - for asking if I was OK and the way she looked after me. I enjoyed it. Actually, they were all very quiet about coming with my dose; I appreciated that. It was also good having the meetings with DoCS in the counsellors’ office rather than in a room in the special care ward. That was fantastic because people couldn’t walk past and see. Otherwise you want to run out of hospital, when the littlest thing happens you want to pick the baby up and take them out of hospital. Some people are prejudice and just little things can get to you.

Then when I was home from hospital I got a phone call to organise for a child and family health nurse to come out to see me. It was good she came because I had a lot of trouble with Adam, he did nothing but cry. Actually one day I had to hold him.
for 24 hours as every time I put him down he would cry. Sally asked me all the questions about sleeping and helped me to figure out what was going on and I got all the answers about normal things. I thought the lounge room would be the right place for him to sleep so I could see him and watch him, but my four year old runs around the house and was quite noisy. Sally was good but when I asked about morphine for Adam and she said had no idea about the dose and everything. I don’t know if they are trained about that, and maybe they should know a bit about what happens when babies are on morphine and stuff like that so they can give more information. Sally said she would come back to see me, but because I was seeing Diane [CFHN at Methadone Clinic] and going there for my dose there didn’t seem much point. I did go to a baby clinic a few times but they were closed. I had a number to ring but it just deters you once you have rung up and you haven’t got an answer back.

Although I only saw Sally for one visit with Adam, I went to a baby clinic weekly for a long time with Liam. The lady there, Mary was fantastic and really non-judgemental and had been there for years; she’s not there anymore, unfortunately. She’d come to my place when Liam was born and I had mental health coming because of what happened with his dad. Mary would sort of be on the same line of questions as the mental health nurses. I didn’t see anything different between her and them, although she would be doing things with baby. Then Mary would address any concerns that I would have with baby as normal, not because of the morphine and me on methadone but normal – like all babies do this and this is why it happens, and that made me feel so much better, to just feel normal.

At the baby clinic, Mary would also ask me how I was and how I was going with the methadone and everything; she was more like a counsellor. That really helped because when it comes down to it, it’s about how I’m feeling and how I am going to cope with my child, especially with what’s happened to me. She dealt with more of my problems than my baby’s and gave me the reassurance mums need to hear, ‘Hey you’re doing a great job!’ You’re usually not getting recognised as a mum. It’s an unpaid job, the only recognition you’re getting is your children growing up and seeing them lovely and strong.

The other place I went to get Adam checked out is by my GP. I remember showing him the baby is on morphine and he is getting it from the hospital and the doctor didn’t say anything, he didn’t need to; it was all oh, oh what’s he doing on that? He is
my local doctor but he didn't know I was on Methadone or maybe he didn't understand the whole morphine thing at the time. I feel like there is a sign on my face, whenever it comes out about Methadone, and the way people talk to me. It's like we're a whole other race sometimes, but there are people that have it, like me and go home and look after their family. You really have to have it because in three days time I am going to be on the bed and, you know, sweating and hot/cold and all the rest of it, so it's more of a physical thing - you've got to prevent that. The doctor was looking very stern at me. He is a fantastic doctor for Nan and Pop and for me for looking over us but when it comes to complications such as a baby on morphine or something I suppose they don't have much time when they have got to see patient after patient. So at the moment I take Liam and Adam to any GP and get what I need out of them and then go. It would be good though for them to just see one doctor.

The other thing to do is to talk to Dr Smith at the Methadone Clinic but she is also a very busy lady, so I can't sort of say look can you check this or can you check that all the time. She was fantastic with the medication part for babies and everything but is more there for that, so I link in with Diane a lot. It's good just to have somewhere to go where they can give you an answer straight away about what to expect with the morphine and other information you need. It all worked out well and Adam got off the morphine. Then I wanted to know what happens after they stop, what happens if he is crying because he's withdrawing? Do I go back to give him some more? Thank God I found out from Diane that you don't do that, because what would have happened if I thought that would work? Oh my God, you can't do that to children! It's normal for a parent who's had a baby on morphine, to think he must be withdrawing, and I must give him some more. After the medication for your baby is finished and the kids are getting older you should probably go to a baby clinic or GP rather than keep coming back to see Diane at the Methadone Clinic, but it's hard to go somewhere else when you're dosing, so there's a bit of a hole there.

So I still talk to Diane about feeding problems and other things, like if Adam's not sleeping. He started waking up a lot during the night again and I tell her all the other things he's doing. I got a referral to Tresillian from my GP but Diane backed me up a lot. Before I went to Tresillian Adam wasn't sleeping in his cot. We had him in bed with us. I was up and down five, six times a night trying to put a bottle in his mouth at 2:00am just trying to settle him. When I went to Tresillian I found out it's actually us learning about the baby's cry, listening and knowing that it is not an emergency.
He's getting his 'leg-cut-off mum' cry; 'I need to come in' scream, or it's a complaint cry, where he'll just cry and then stop, cry and have breaks. In those breaks he's learning to self-settle. I didn't learn that until I was with the nurses at Tresillian because you're just so worked up. So we got the music at Tresillian, dark lights, and the right atmosphere for him. He got used to being wrapped again so that's like being in mum's arms. He's comfortable and also he's contained. It stops him from jumping up and holding onto the bars screaming 'mum, mum!'

Adam's at the age now where he's like a sponge, absorbing everything. He's doing everything - one day or a week there's something different. He's changing every day. One day he might be a bit of a grump because he's either got a nappy rash or he's teething, but I've learnt to still put him in the cot and just be aware that yes he may cry, he might need a bit more settling. I don't have to put everything down and rush. That's what it was like before Tresillian. It was more you're trying to do it but you're not getting the information that you need to know. You're just doing what you can as a mother and lots of mums I find are like that. I found out I'm actually really normal because I take my medication. Mums in Tresillian are having the same problems I'm having.

When I come back from Tresillian, my partner got out of bed started arguing about the baby crying. He could have come up to Tresillian and did what I did but he chose to undermine me and take over, in a way. I use to get angry and yell at my partner saying 'look at the kids the kids are watching this and doing this.' But not actually sitting down with the kids because I'm too busy arguing with him trying to put my point across, which is hopeless. I use to get my four year old to go to his room, but he still would have heard it. This time I've done things to backup the safety of my children which is very important; he's not at the house any more. Being a mum and being able to focus on my kids is even more important. When I look back at the photos, Adam looks so tired and I was so tired myself. It was only when we got that rest that I found out 'Hey, this is a new world, motherhood, enjoyment!' Things that have happened in the past have affected me but since coming back from Tresillian I've been able to really enjoy being a mother. Actually walking in the baby's room knowing before I go in there what I'm going to do - no eye contact, the sleep time, the settling.

I have had some traumatic things happen but this is the best part of my life now. I've got Liam and Adam and I couldn't be in a better place because I've got people to
turn to if I need help. If I'm having a bad day I can talk to Tracey my case worker [methadone clinic RN] or someone else; they see me, they are behind me, they are helping me. I think Tracey has a course ‘keeping families together’ or something like that, which is good to know. You get so worried about your child being taken away for being on Methadone, or for other reasons, and so that really helps when they tell you they want to keep your family together. It is just you might have one or two things to meet to do that. I’ve got a lot of good people helping me. Tracey, my case worker at the Methadone Clinic is like a sister to me. Like Diane, she’s helped me a lot with the positive stuff, and knowing about normal child behaviour.

As well as Tracey, Diane and Dr Smith the other people I see are Debbie [speech therapist] and Kathy [child care worker] that run the play group at the Methadone Clinic, my prescriber and Lyn, the psychologist. Playgroup’s fantastic but the ladies there and I had a problem with all the smoke butts that were left around which shouldn’t happen because the hospital grounds are supposed to be smoke free. I worry because my little one puts things in his mouth. They have cleaned it up but it took a lot from the ladies of playgroup to get them to move to do that. Otherwise, playgroup’s great. I like being able to come to playgroup and talk to the ladies, be relaxed that I'm supported and feel like a normal mum. In a way I'm watching them [staff] to see how they are talking and playing with the kids. I've seen the way the children respond and I'm getting back to that.

Coming to playgroup and to see Diane helps me get other problems sorted out too. I have problems with my four-year-old and his speech. We baby talked to him a bit when he was younger so now he’s just getting those things out. Debbie makes an appointment available at the Community Health Centre for children from the playgroup if she notices they need help with speech, which quite a lot do. The other thing Liam needs is dental as he’s got a black tooth at the back from a bit of sugar and Diane said she can get me and the baby in to see the dentist too. It's important to have resources like that and other things that I would have left not done. It's good to have that all-in-one spot here because it's hard to get to the Community Health baby clinic. I'm capable of doing that, but just sometimes you've got so much to do. I've got to cook dinner, I've got to think about this and that and all those things play on my mind.

In the past, I had counselling through the Community Health Centre for domestic violence and also had grief counselling. Mental Health was involved, but I haven’t
had contact with them for a while now. The psychologist comes to the clinic every week to speak with me and it’s definitely good to talk to somebody and get everything out. I do get a little bit depressed and I can feel like a robot, you know, working around, doing the washing up, doing the washing, looking after the kids. My night finishes 9 o’clock and I’m in bed and that’s it; I’m dead to it. I need to find some other things in my life and that’s what we are working on. Take a walk or have a bath, because when I become stressed I can’t look after my children. I thought I could just look after them and I’d be fine, but it’s not the case, I need to look after me so I can look after them. It’s finding the time. Look I have had a great gap with a four year old to a seven month old because Liam is going to be in pre-school and then I will get time with Adam which will be better than at the moment, so that’s really good. I’ve got Mike’s mum as well as Nan to help and give me some time to myself and everything, but I just like to do things myself. I will do anything for anyone else but I’m starting to understand I need to have a bit of time for myself and my wellbeing; for my head.

My biggest goal is to keep the children and not only to keep them but to do the right thing by them. It’s no good me having them if I am abusing them or I am going out doing stuff. I’m not giving them the life that they could have. It’s a vicious cycle that keeps going around and around unless you put your foot into it and go ‘no more’. I’m going to change this and make it because otherwise you pass it down to them. My mum passed it down to me. I really do believe that. My first impression of DoCS was that they are going to take your children because they did it with Matthew. My first DOCS worker said, ‘Any children you ever have, I’m going to take off you’. Like basically saying I’m not a mother, bottom line. She was taking her job way against that badge. She was holding that badge up – but that almost devastated me for life, thinking that I could never keep my children. Then I had another DOCS worker that said ‘Hey, we don’t like taking children off families unless it’s really necessary’.

I suppose to me, I have to work with DoCS if I want to have my children. I’ve learnt that if DoCS are going to be in your life to monitor you, use them to your advantage by letting them know things. If something happens they will come out and see you and give support, helping me with this or helping me with that. If they’re going to be in my life they may as well be there for a good reason. My DoCS worker is a really young girl, younger than I am and if my partner saw her when she first come out, he’d wonder if she could do the job because she’s younger than us. But you’ve just got to work with them rather than getting stuck on that or going oh no, it’s DoCS!
I’ve learnt it’s about doing the things you should be doing as a mum to be able to keep your children.

I’ve also been going to a place called Newpin where I can learn to play with my children and get extra help. I really enjoy going there. Usually you have to have therapy too, but I don’t because I’m already seeing a psychologist through the Methadone clinic. I think it’s fantastic at Newpin because they do lots of things around the care of kids and keeping families together, and it helps to talk to other mothers about stress with the kids and stuff. Otherwise when everything gets too much it becomes a mental health issue a lot of the time, like depression and anxiety. I mean it’s happening all the time, you see it on the news, you know, mothers kill their babies and this or that. I don’t know what brings you to do that, but how come they didn’t talk to somebody? It’s because they don’t feel like they can.

There needs to be more a lot more places like Newpin or places you can go or ring and you are not judged. At Newpin they say look we are mandatory, but that’s OK because sometimes DoCs have to take the children and need to put things into place so the kids are safe and achieving everything they need to. On the days I’m having dramas I notice the kids are having dramas. They’re screaming and fighting together and I’m pulling my hair out. It’s all WWIII! I can go to Newpin and talk to the ladies and that helps normalises it all. I can ring them they come pick me up. That’s what a call for help is. It’s not about wanting to kill yourself or doing this or that. It’s more that you’re stuck in the moment you don’t know how to move forward. You’re reaching out for help because you don’t know who to go to. I’ll also ring to talk to Diane or Tracey or one of the other workers at the Methadone clinic and they’ll ring me back to make sure I’m okay. I’ve got that extra support with a case worker and she can give me the numbers for Debbie for speech therapy or anything I need that I can't think of by myself.

In the past I previously tried to deal with things with drugs, with cones or valium, but it makes it worse in the long run. I want to get back to work, to be acceptable in society, have a break from being a mum and keep myself busy and organised. The goals are there for the aiming for the future. I think it's important for my kids to look up to me. But without my Nan and Pop and without all the support I’ve had from lots of people it would be hard to keep going some days. You need to have hope, and it's the strength of a whole community that helps. If I can't then I'm going to fall back. I’m going fall back here and I'm going to fall back there and they're going
make me okay for that day and I'm going to get pushed up. My friends around are supportive and say, hey we're here if you need to talk. Everything helps so that's where I am.
Appendix 10

‘DANIELLE’S STORY’

‘I could tell she wasn’t sure if I could do this motherhood thing’
I was fourteen when my eldest sister, Kelly died of cystic fibrosis. That was 16 years ago; she was only twenty-one. A couple of days before Kelly died my second eldest sister took off with her boyfriend because she was sick of being expected to help in the house and be a second mum while Mum was working and looking after Kelly. Mum had left Dad because he’s an alcoholic and she was trying to make ends meet. I also had another sister but she died from cot death the year before I was born. I started drinking and smoking pot when Kelly died; I was very close to her. I carried the grief for too long, as I wouldn’t talk to a counsellor about it. If you do rehab, you have to do counselling, to work through all the problems that got you there. If you don’t, you just go back to square one.

I’ve been to rehab three times, the first two were live-in ones. I got kicked out of them because of a fight the first time and drinking the second time. I let other people influence me and made some bad decisions but it was my fault as well. Then I decided to get serious about it. The last rehab was a three month program and I had to travel there every day, which was harder than the live-in because when you left each day there were lots of influences around. In the beginning I was going to give up, but I persisted and they let me stay longer because I didn’t open up straight away. That was two years ago, and I’ve managed to stay off everything since then. I’d been on medication before, but without the counselling. I couldn’t talk; it was like some sort of depression. I was just really quiet and didn’t want to talk or do anything. I didn’t want to talk to a stranger about my problems. But everything’s turned around now. I’m a new woman, I’ve done it! I’m only on the buprenorphine now.

I’m still hating myself for being on the bupe, especially when I was pregnant with Sam. Growing up, I use to look down on people who were pregnant and going up in their methadone dose because of the baby growing. I thought it was just bullshit and they wanted to get stoned. At first I couldn’t believe that I was actually on it, but then I think that it’s helped me to be where I’m at today. They told me Sam might need some morphine after he was born; I thought ‘what, no way’! I didn’t like that idea, but he didn’t need any and I was so happy. When I have another baby, I want to get off the bupe first. Even though Sam was alright; the next one may not be, you just don’t know.

I wanted to go back to the drinking a couple of weeks ago because I was upset and stressed because my Nan died. I knew I wasn’t stable but I didn’t want my bupe
dose to go up, because it would take longer to get off it. But I ended up talking to
my case worker about it and I’m alright now even though the dose did need to go
up. It was the grief that got me into the bad lifestyle when I was younger, and this is
the first time that I’ve been through grief since then. I think I handled it pretty well
because of what I learnt in rehab; just allowed myself to grieve instead of bottling it
up.

I got married to my partner about 6 months ago after being together for over two
years. Steve is my main support. He’s clean and never used drugs. He did use to
have a drink, but he’s stopped because I was an alcoholic. He isn’t the type of guy
that I’d normally go for but he helps me to move into the life I want to make for
myself. Sam’s my first baby and we had planned to wait until I finished my Bachelor
of Arts degree. I was only eight months into it when I fell pregnant but I still plan to
go back and finish or do nursing or become a drug and alcohol counsellor. When I
was younger, I wanted to be a nurse, but I changed my mind when Kelly got sick.

I didn’t believe that I was pregnant at first. I got some pregnancy tests from the
nurses at the Methadone Clinic, but it wasn’t until I’d done four tests that were
positive and had an ultrasound until it sunk in. I was that happy to be pregnant! I’m
thirty and I hadn’t wanted to have a baby when I was drinking and stuff; it’s not a
good scene to have a baby and put a child through that. So I was really happy to be
pregnant, to have a little miracle. A lot of good things were happening for me, and it
was good to be pregnant. I had a bit of reflux and was fine until I got some high
blood pressure from when I was five months pregnant. It was really stressful
towards the end because we ended up being homeless just before Sam was born.
We’d been living with my mother-in-law but we couldn’t stay there and moved to a
caravan park when I was about five months pregnant when we couldn’t get a private
rental. Then back and forwards to the Department of Housing because
it was too
expensive. I actually had to go down twice a week and ring up the homeless line
every other day. I was really stressed because all I wanted to do was to find a
home, to secure a home for my son before he was born. We eventually got a house
and I went into labour that night! He was two days overdue. I get teary just thinking
about it; it was a really hard time, it was terrible. But we got through it and despite
all the stress, not once did I think about drink. I was thinking about my son, and I
wouldn’t drink being pregnant with him.
During my pregnancy, people at the Methadone clinic were really good but it felt like some of the doctors or others at the hospital judged me. As soon as they know you’re on buprenorphine or methadone they make assumptions. So I was judged a bit and that really annoyed me. I shouldn’t care what people think, but it seemed like they were saying that I was a bad person for being on the bupe. There was even a misunderstanding with my doctor at the methadone clinic at first. I’d asked the nurse if my dose could come down, but they said no because it would have to go up eventually because I was pregnant. The doctor said that the nurses wouldn’t have said that and that I didn’t need to be on the bupe. He basically called me a liar. He was very judgemental about it until he found out my story, then he was a lot better. I’d been clean and had clean urines, and had only been on the bupe for a certain period of time. Then he was really good, he’s excellent.

I wanted to have a natural birth but I ended up having an epidural when I was seven centimetres. I tried the gas first, but I didn’t like how it made me feel. I thought that it would be good but it made me feel stoned and I hated it, I really did, and wouldn’t take it anymore. The midwives were really good, they were excellent. I ended up going through three midwives, I was there that long. They were really supportive, telling me the best things to do because I was refusing pain medication at first. I didn’t want anything because I wanted to do it naturally. So the midwives suggested a hot bath or hot pack, and they’d rub my back, they were really good. My husband was there and he got photos of the birth. It’s just amazing how the whole process works! I actually really wanted my mum to be there too, because two of my sisters passed away and the other one disappeared. We haven’t really had much of a relationship until I was pregnant and came clean and she saw me turn things around. So I really wanted Mum to be there, but she was four hours late even though I’d been in labour for two days.

Just after I had Sam, the midwives came and said they had to take him away from me! That he had to go to NICU and I had to go up to the ward. They'd only just put him on the nipple, I couldn’t believe it; I was shattered, I was a mess! I thought, you can’t take him off me; my doctor had said that Sam wouldn’t need to go there, and that he could come upstairs with me. Like don’t take him off me, he’s my son, give him back! But that first night I was away from him. It was terrible because I’d just had him and they were taking him away from me. I was so angry because I couldn’t understand why my baby couldn’t be with me. At the time, I could only think, ‘You can’t take him away from me!’ They kept Sam in NICU until my doctor from the
methadone clinic fought to get him up with me. On the ward they were treating me a bit differently, so the doctor spoke to them and said that there was nothing wrong with me or my baby and that Sam could stay in the room with me. That doctor turned out to be really good in the end; he was excellent; just that first impression wasn’t so good.

Breastfeeding didn’t get off to a very good start because I missed Sam’s second feed. I hadn’t slept for two and a half days while I was in labour, so to catch up they advised me to sleep through his next feed. When I went back to NICU, I was surprised to find that Sam had a tube in his nose because they said that he hadn’t been feeding well with the bottle. He was doing fine with me, so after that I didn’t miss a breastfeed and my doctor told them to take the tube out. Then on the ward, I was told to breastfeed in nursery. Other mothers could take their baby back to their rooms to feed, but they wanted me to breastfeed in there so they could see. I felt really uncomfortable because there were male visitors coming in and out with their wives. I asked if I could breastfeed him in my room because I’d showed them long enough what I was doing, but they said no, no, no. They said no, he’s got to be watched a bit longer. I thought that I was judged a bit because I was on the bupe and they treated me differently. It annoyed me a bit, but I was actually quite proud of myself and surprised at how well I handled it. I just went with it and did what they said. I still felt a bit judged because sometimes they’d give Sam a false score and that would effect if he was given any morphine. Every baby can sneeze or do certain things, so I thought the score was false. I know that there are mothers out there who do bad things when they’re pregnant and the midwives were just trying to do their job. I took it personally in the beginning but after a while I weighed it up and thought they were making sure that I was doing the right thing for my baby.

I enjoyed breastfeeding. Maybe it was the closeness I had to him. I’d just sit and stare and watch him, fascinated at how well he just went into it. I enjoyed the moment and that special bond between us that no one could take. I ended up breastfeeding for about 10 weeks. I was disappointed to stop, but he got sick with colic and reflux and we changed him to an anti reflux formula. But I loved it. While I was in hospital I went to the classes on how to bath him properly and how to wrap him properly and all those sort of things. They gave me all the forms before I went home and where to get help. It was wonderful to be able to take Sam home. I still felt in shock that I was actually a mother because it was something that I’d wanted for so long. I was worried at first that I wouldn’t hear Sam when he cried and all
those natural worries; I did of course. I talked to my mum about it and she said that my natural mothering instinct would come and that I didn’t need to worry, but at first I didn’t think that it would!

After I went home, I had a phone call about a child and family health nurse coming to do a home visit. They didn’t ask if she could come, they just said she’s coming. I thought it would be good to make sure I was doing everything OK, but after I met her on the first day I dreaded her coming for a while. The child and family health nurse, Rosie use to come over every couple of days to weigh Sam, check him out, and make sure I was being a proper mum. To make sure I knew what I was doing and I wasn’t stressing out. She asked lots of questions, trying to find out if the stress was too much for me and I was drinking, without actually asking me. I know that it’s her job to make sure the baby’s in the best place, but it sort of pissed me off in the beginning. She also wanted to know if my partner and I were fighting and talked about not leaving Sam on the lounge or anywhere that he might roll off and hurt himself. When I was feeding, she’d also make comments about making sure that we were feeding him enough, and pretty much making sure that we were looking after him. Like she’d say it in a nice way, but there was always a funny sort of question behind it. The way she said it was in a roundabout way, she was sort of smart about how she said it. It’s hard to explain, but I could tell that she wasn’t sure if I could do this motherhood thing. I know it’s their job, but maybe because of my history and my being on medication, I was definitely judged, definitely.

I wasn’t very confident as a mother to start with, and hoped that I was doing things properly, but after a while I got into the swing of things naturally. The child and family health nurse gave me some information on a course about understanding your baby’s cry. I was going to do it, but I learnt it all naturally by myself. If you just spend time with your baby, you can just figure it out yourself. But Rosie was a good help letting me know where I could get support or get his needles done or other things. But in the beginning, she was a bit judgemental and I use to dread her coming. I can’t quite remember the exact words that she used but I remember the way it made me feel and she insinuated that I was a bad mum without actually saying, ‘You’re a bad mum’. But I was just a new mother. There’s a difference between being a new mother and getting advice and help from people or getting criticism like they don’t think you can do it.
I suppose they might look on me as a bad mother and maybe not take my questions as seriously as they would for someone who has never been on drugs. If you’ve been on drugs you’re definitely judged straight away or when people have read your history. You can just tell by the way most of them speak to you. They don’t have to say, ‘I’m going to judge you because you’re a drug addict’. Sometimes when I do ask for help or do ask a question, they automatically turn around and ask how I’m feeling, ‘How are things going for you?’ Maybe they’re thinking that I could be drinking again. I’d much rather they’d ask me in a direct way, being honest about what they are thinking, instead of going in a roundabout way. I’m not stupid!

Eventually, after a few visits I actually said to Rosie I was getting the impression she thought I was a bad mum. She was different towards me after that, in a better way and I sort of mellowed down a bit with her.

In the end I didn’t mind the child and family health nurse coming. She could give me guidance and reassure me that I was doing everything right for my son and if I had any questions about Sam or was worried about him, she would help me. It was a good service and she also gave me numbers to ring if I had any questions through the week. She ended up being lovely and praised me and it was like ‘you’re doing a good job, you should be proud’. It was just the way she was sometimes that I didn’t like. When I look back on it now, I guess she was just doing her job and maybe she’s been in a situation where someone that use to be an alcoholic on methadone or bupe didn’t look after their baby. I suppose they also wanted to make sure I was OK and wasn’t getting postnatal depression. She did judge me straight from the start though.

The visits became weekly and by the time Sam was about two months old, Rosie could see that I was comfortable and relaxed with how things were going. She said that she didn’t need to see Sam anymore, and that I could keep him. The way she said it really annoyed and upset me. I thought, ‘I’m not going to give you my son, don’t even joke about it; what do you mean you’ll let me keep my son?’ It was like I’d passed a test, but I understand why because in other situations there might be a bad mum. It all got to me at the time because we’d gone through a lot with being homeless and having a baby.

I haven’t been to a regular early childhood health clinic with Sam but I take him to a GP if he’s sick or something. I’m looking for a good one at the moment, someone that’s willing to do the thorough tests. Sam was referred to see a paediatrician at
the hospital when he had reflux and colic and now we have a follow-up appointment every three months. He’s excellent, and does a thorough check and I’m happy with him. The paediatrician told me to change the formula and then he was better, so that was good. Sam’s had all the developmental checks done and he’s perfect.

I’m now nine weeks pregnant with our second baby and my husband and I are both happy. We had wanted to wait nine months after Sam was born to become pregnant, but it nearly worked out like that. I’m disappointed because I wanted to get off the bupe before I had another baby. Sam didn’t need medication, but I think he was uncomfortable at some stages and I didn’t want to put another baby through that. He’d sleep for 40 minutes and then wake up screaming, it was terrible seeing him going through that. It was hard being separated just after he was born.

I was devastated that Sam went to NICU because my mum didn’t know I was on buprenorphine. It was on my file and I told the nurses not to mention in front of my family, but a doctor did, so my mum found out about it. He asked me if Sam was on the same medication that I was on in front of my parents and my husband’s parents! I had to ask everyone to leave so I could talk to him in private. Mum was devastated; she was really cranky with me even though she didn’t show it at first. She was disappointed that I hadn’t told her and thought that I was on buprenorphine because I’d been taking heroin or something. She didn’t want to listen to a ‘junkie’, but I explained that I was on it for the alcohol and the takeaways of methadone that my father-in-law’s ex-wife had given me. After a couple of weeks, she was alright and I felt much better after the truth came out because I can’t lie to the people I care about. My husband’s family think I’m picking up depression pills. I hate lying, but they’d judge me for it.

So I don’t know how things will go this time with the pregnancy and everything. The vomiting and tiredness has kicked in and it hit me really hard last week. I was saying to the nurses at the methadone clinic that I’d forgotten about all this and they said ‘how could you forget!’ They’re excellent. If things bother me, I talk to the nurses when I come for my methadone. I was telling them that I was having problems putting Sam to sleep on his own because we rock him to sleep. I wanted to get some advice because I’ve had some trouble with my hand and I didn’t know how we’d manage with a new baby too. They gave me some information on what to do which I’ve read, and I’m going to see Fiona, the child and family health nurse.
when she comes to the methadone clinic on Wednesday. I’ll ask her for a bit more advice and for a referral to Tresillian.

After the baby’s born I think I’ll get Fiona to come and do the home visit. She offered to do it last time, but by then I was already linked in with the other child and family health nurse from the community health centre. I think Fiona will have more of an understanding of what it’s like for people on bupe or methadone because she comes and works at the methadone clinic. It’s a very judgemental world even if you’re not on bupe or methadone; very judgemental. Last time, the other lady turned out to be good in the end, but I definitely won’t see her because I think she was insinuating that I was drinking and that I wasn’t a good mum. She gave me the numbers to her clinic if I wanted to go there, but I felt judged and uncomfortable in my own home. I thought maybe it was because I was a new mother and the hormones were making me think that, but my husband thought the same. So this time around we’ll stick with Fiona. It’s like with counselling, you can’t always talk to a person.

The staff at the methadone clinic are really great with support no matter what, whether we have a baby or not, they’re really good. They’ve helped me through a lot and helped me keep sane and strong after some of the things I was going through. I open up and tell them my problems because they’re not silly and are aware that when I say I’m alright, it doesn’t always mean that I’m OK. Sometimes they can see something’s wrong and they’ll push me a bit saying, ‘Come on, you don’t look OK!’ They’ve been really great.
Appendix 11

‘NICOLE’S STORY’

‘she showed me the most amazing thing that I’ve ever seen’
It’s important for me to tell my story so that people know what it’s like to be judged, and what it’s like to be a mother with a methadone baby. I never dreamed that I would have a baby on methadone and although I try to be a really good mother, it’s been really hard at times. People don’t always believe you. But I’ll start by telling you about how I got into this situation.

I’m twenty-one and the middle child of seven children my mother had to three different partners. When I was little, my step-father sexually abused me and beat me up. I was so scared, I didn’t tell my mum or anyone else about it until I was sixteen. When it all came out there was a court case which was just horrible. I had told them that my step-father had also abused other girls, but they didn’t follow it up. It seemed like I was making it all up and he was going to get away with it. I thought that I was finally going to have my say and finally stand up to him and he was finally going to pay for what he’d done, but it was more like I was on trial not him. At the end the judge basically called me a liar so I was just a bit shattered after that. It’s really hard to get back to normal after something I’d been waiting so long for finally happened and it turned out like crap. It was like, that’s it, get on with your life; it’s a bit harder than that.

I got compensation and I had all this money, so I went on holidays overseas. I was meant to be happy and fixing my life up, but a whole lot of things happened and when I got home I was really down. I just wanted to be all better, but I felt like rubbish and I was really sick as well. I started to ask my boyfriend for some heroin to help me feel better. He’d been struggling with heroin in the four years that I’d known him. One night he gave me some to smoke, rather than inject because he didn’t want me to get hooked on it. This was OK until we got assaulted and I was feeling really stressed out with everything else going on too. From then on, I started injecting heroin. Around this time, I noticed that I hadn’t had my period for a while and my boobs were getting bigger. I was in a panic as the pregnancy test was positive. What to do? What was the heroin going to do to the baby? Some people tried to get me into a rehab centre, but they won’t take you if you’re pregnant. I also thought about going cold turkey, but I had nowhere to stay. I didn’t know what to do. I couldn’t tell my family that I was on drugs and I was pregnant, that just wasn’t an option for me at the time. So I went to the hospital.

By this time I was three months pregnant and I was worried about the baby. Everyone who spoke to me was worried about the baby and kept telling me that I’d
have to get on the methadone. But I kept saying, no, I really don’t want to get on it. I was thinking maybe it would be crueller to have the baby than to lose the baby. I don’t like abortion, that’s something I’d never even think about, but I was thinking maybe it’s a more selfish thing to get on methadone than to have an abortion. I was petrified to get on methadone because a lot of people who get on it never get off. A girlfriend’s mum was on it; her kidneys failed, she had a stroke and died. So it’s a very scary thing to go on methadone, it’s petrifying. I never, ever dreamed that I would end up on methadone, let alone having a baby too. The doctor in emergency talked to the drug and alcohol people and they said that I just had to get on it. I started digging my heels in and said no, but he got a bit stroppy with me and told me that I really had to, because I wasn’t the patient anymore, my baby was the number one patient. I guess that was right and I needed to hear that at the time, but maybe he was a bit hard on me. I don’t know what would have happened if I didn’t go on the methadone, but I’m really glad that Sophie’s here.

I initially agreed to try it for a few days, so I didn’t lose the baby and because I had nowhere to go. I felt like I wasn’t being a good mother and wondered how I was going to get off the methadone later. The dose they started me on was way too high; I felt like a zombie. I couldn’t get out of bed; I was just a vegetable, a drooling mess. What was it doing to my baby? Poor baby. The doctors only came around before I had my dose and they wouldn’t believe me that the dose was too high. The nurses believed me, they told the doctors and wrote it in my notes, but the doctors just wouldn’t listen. I even said please come at a different time of day so you can see how much it affects me, but they said they were too busy. If I didn’t take one of my doses they said that they’d put in a DoCS report saying that I wasn’t cooperating. They just treated me like I was being rebellious, but I was genuinely concerned that I was getting way too much methadone.

Eventually I gave up fighting the doctors about it. By that time I’d talked to some really nice people and I’d decided that I needed to make the best of the situation, to do whatever I had to so I could come out the other end of it and keep my baby. I wrote out pages and pages of everything I wanted to know before I had the first dose. What effect the methadone would have on the baby? What would happen when I had the baby? I wanted to know everything and I sort of feel like they told me anything to go on the methadone. They said most babies are completely fine, but may need some medicine for a couple of days and that’s about as bad as it gets. So it was a complete shock to be told at the end of my pregnancy that she’d have to
go to NICU and it could be for up to three months! I’m like, what? I’m going to give birth to my baby and it’s just going to get whisked away from me for months and on the bloody morphine? I didn’t know anything about this!

By this time, I’d moved back with my mum so she knew that I was pregnant, but she didn’t know that I was on methadone. I had to make up an excuse every day to go and get it. I had most of my antenatal checks at the local hospital, but I had to go to the bigger hospital where I was going to give birth for the last three weeks. The birth ended up being fine – I had an epidural so that helped! But I only got to hold her for five minutes before the midwives took her down to the NICU because she was a methadone baby. I felt really low and upset about that. How can they take a baby away from their mother? Before I started on the methadone they’d said that the baby stays with you and only goes to NICU if she needs to. It was just horrible because I really wanted to go down there but I couldn’t get up because of the epidural. I just wanted to be with my baby. I was waiting for hours for a wheelchair to go down to be with her which felt a bit sort of surreal at the time.

While I was waiting, some midwives came in with forms for me to sign so that Sophie could be vaccinated. I was all out of it and didn’t want to decide what I wanted to do at that moment because I wanted to read it through and think about it. I think they pounced on me then because mum had left the room. They started to really get stuck into me about it and one of the nurses actually said ‘Because of your risk taking behaviour, your baby’s at risk of getting diseases and if you don’t do this you’re really selfish’ and she was just so horrible. I was just lying there not knowing what to do, and feeling bullied into making a decision then and there. My mum didn’t know that I was on methadone and it seemed like a threat that if I didn’t hurry up and sign she’d let on to my mum about it! I’d only just given birth and I felt pressured and bombarded by how they were talking to me. I ended up signing for the first needles but said I didn’t know what I’d do about the rest. I was annoyed and upset that I hadn’t had time to think and was almost bullied into making a decision that I wasn’t sure about. My mum had decided not to vaccinate me, but I wasn’t sure what I wanted to do.

I had the same problem a couple of days later when two midwives came in with the rubella vaccine for me. I was sleeping because I’d only been nodding off in a chair for half an hour here and there and was really stuffed. Mum came in to mind Sophie in NICU for a few hours while I had a sleep. I was sort of really out to it when they
came in and I was still half asleep when they were telling me that I had to be vaccinated for rubella. When I said 'No, I don't want to get vaccinated' they said 'Come on, you need to be vaccinated or you're at risk of infecting your child'. Anyway, I got vaccinated. I don't even barely remember what happened; I was so out of it. So I was a bit annoyed that I didn't make the decision to vaccinate or not vaccinate. I was disappointed that I didn't really have a say, same as I didn't want to sign those papers for Sophie at that time and just didn't have a say. They made me feel guilty if I didn't.

Eventually I went down to the NICU, but the nurses didn't really tell me much. They just told me that they look after the baby and the parents come and go, and sign this to give her formula and sign these other things too. I said that I wanted to breastfeed and they explained that the formula was only if she needed it. They didn't really explain that I needed to feed her every three hours and to make sure that I was there for a feed and to change her nappy. So I missed some feeds and they gave her formula. Then it was hard when I did try to breastfeed Sophie because she'd had bottles of formula, and I wasn't sure what to do. She is my first baby, and I didn't know what to do and they weren't very encouraging. It was embarrassing that I didn't even know how to change her nappy. It was all a bit daunting. There were a few nurses in the NICU who were really nice, probably the majority, but a few made it really stressful. So when I'd come in, I'd see who was there and either think 'oh, good' or sometimes 'oh, no'.

The nicer nurses would just chat to me like normal, like they'd chat to all the parents in there. I met some really nice people who were lovely. They were kind with Sophie and just treated me how I you'd expect to be treated, just normal and not insulting, really professional. But there were a few that were judgemental, even if they didn't mean to be. They'd dismiss what I'd say and just because I'd had her on methadone I must be a bad mother, so don't take any notice of me. Like how could I want the best for my child, how could I possibly love her on methadone? So they didn't really listen to me when I was trying to talk to them about how they were scoring Sophie for the morphine.

Although it's upsetting that I had her on methadone, it's not that I didn't want her to have the medication. I would have preferred that she didn't need it, but I would prefer that she had it rather than suffer. I told the doctors when I first noticed that Sophie was sweaty, because I didn't want her to be uncomfortable and they said
that they might start her on a very small dose of morphine. Later, I noticed that when the
erlier nurses were on her score would be really low and when the other ones were on, the score would be really high. I was just trying to get the honest result of what the score was meant to be, because that had an effect on how much morphine she had to have. She started to look like she’d had too much because she’d be extra sleepy and start to go floppy. Whenever she cried when I was breastfeeding she got marked for poor appetite and not being able to suck properly. They tried to tell me that she was crying because she was withdrawing, but I tried to explain to that she just wasn’t use to the breast and she gets a bit angry like any baby would. She was also getting marked for being unsettled, even though the rest of the day she’d be settled. So that bumped the dose up another couple of mls every time, and every time the score would go up, the dose would go up some more. But they didn’t want to know. I wasn’t in denial that I’d had a baby on methadone, I know that, but I genuinely just wanted what’s best for my baby and I wanted to breastfeed.

It was really hard to get going with breastfeeding. Early on, one of the nurses was a bit abrupt and not very patient so she grabbed the baby and grabbed my boob and put it in the baby’s mouth. I was crying and the baby was crying and it just wasn’t working and she was getting frustrated. Then Sophie was crying because she was hungry so I’d give her a bottle and she’d just chug it down and be content and asleep. I ended up not breastfeeding in front of the nurses because I was getting upset and it was impacting on Sophie’s score. The whole thing was really frustrating so I couldn’t really breastfeed her in there anymore because I was getting stressed. So I expressed and gave the breast milk to Sophie in a bottle so they didn’t unnecessarily bump up the dose of morphine if she didn’t need that much.

It felt like it would be easier for the nurses if parents weren’t in the way and asking questions and all that stuff. They don’t really encourage you to be with your baby; maybe they think that they’re their babies. Also, I couldn’t believe that after two days they wanted to sign me out of the hospital. Like we’ll keep your baby here and you just go away, visit when you can, and pick her up when we’re ready to discharge her. I never got told anything about me having to go home and them keeping the baby! As far as I knew, I would be in the hospital that whole time, spending time with my baby. I was so upset that my mum spoke to them and we ended up having a meeting. They said I could use a room in the NICU for a couple of days, but my boyfriend wasn’t allowed to be there (DoCS didn’t mind but mum was feeling cranky with him because he wasn’t at the birth).
I ended up having a run in with the head nurse who accused me of lying after Luke came in one night to keep me company. We were both getting really tired in chairs next to the crib and the lovely nurses who were on said we should crash in the room they said I could use for a couple of hours. I tried to explain what happened but she was really rude and didn’t accept that I was trying to do the right thing. She came back later in the day and said ‘Good news!’ They’d organised to transfer Sophie and me back to the hospital where I had most of my antenatal checks. I think she was glad to get rid of me but I was stoked because I hadn’t been able to stay with Sophie since she’d been born and I’d have a bed in the same room. So I was just really happy and was on the top of the moon when she told me I could leave.

I had a much better time in the other hospital, even though breastfeeding was still a challenge. So many people tried to help me in both hospitals. If anything it became a nuisance; like get away from me. It would always become an ordeal with them grabbing at me and the baby, and the baby crying and me crying and it would just end up being horrible. So whenever anyone came up and said ‘Oh, you’re breastfeeding’ I thought great, here we go again. Until I saw Sandra when she came to visit me after I moved back from the big hospital; if it wasn’t for her I wouldn’t be breastfeeding now. Sandra’s a child and family health nurse who also works from the methadone clinic I go to once or twice a week and she knows a lot about breastfeeding. Instead of telling me what to do she said what a good job I was doing and how good breast milk is for babies and all that sort of stuff. She showed me a few different positions that might be good and that you can lie down to breastfeed. Then she showed me the most amazing thing that I’ve ever seen. Sophie was just in a nappy and I was topless lying back in the bed. Sandra put Sophie on my stomach and the baby did like a little commando crawl up and got to the breast herself and latched on! It was just really amazing to see a baby who I couldn’t even get on the boob properly do all that by herself! It really helped me to keep trying to breastfeed.

When I went home, Sophie and I eventually figured the breastfeeding out. At first she’d go to the breast but end up crying and not feeding properly, so I’d give her some expressed milk in a bottle too. I was expressing all the time and was getting so tired expressing at night and having her on the boob. My mum’s fanatical about breastfeeding but even she thought it was all too much because I was miserable and going around like a zombie. I was so close to giving her formula because I was
so tired and expressing so much. For a couple of nights I just couldn’t be bothered, I just wanted to go to bed, so I just whipped my boob out and went back to sleep – it was that or nothing. It was a bit slack that I couldn’t keep up with the expressing and she was sort of forced into breastfeeding, but I was at the end of what I could possibly do. After a couple of nights it became a nightly ritual and eventually I didn’t need to express in the day either. Sophie’s nine months old now and she won’t even have a bottle at all.

After I came home from hospital I walked up to the Methadone clinic with Sophie and when Sandra was there she’d come out and have a chat with me. I had a lot to do with her because I went to the clinic to get dosed during my pregnancy. It’s really good having a child and family health nurse there so that people who have kids and have problems can ask things. After a while I was able to get my dose from the pharmacy as take-aways, which was good. I could take Sophie to the shops and feel more like a normal mum. I felt like I was the only person who’d ever had a baby, yeah that was good.

As well as talking to Sandra, I also asked Robyn, the child and family health nurse from the community health centre lots of things. Robyn rang me up after I left hospital and we organised a time for a home visit. I was a bit worried because the house was messy because I had baby stuff everywhere, but Robyn didn’t mind. She’s great, and knows lots about everything I have to ask. It was exciting to get Sophie weighed and see how much she’d grown, and even to have a chat about the baby and all that stuff. With most social workers you don’t really look forward to the next visit, but I really looked forward to Robyn coming. She’s nice and it makes a big difference if the person’s nice and if they know what they’re talking about as well – both those things. She told me about bathing the baby, and I got advice on things like thrush in Sophie’s mouth and nappy rash. If they know, if they actually know what they are talking about and it’s helpful stuff, it makes a big difference, because sometimes people tell you all different things and it’s not helpful. Robyn was nice, but she was also professional about her job. It’s not their job to teach people a lesson or anything like that. It’s so easy to end up in a situation that you never dreamed yourself to be in, but something happens and you end up being judged all the time.

I did feel judged by DoCS and was really annoyed at how they treated me in the end. It was OK in the beginning because I expected them to be involved as I’d had
a baby on methadone. But I was planning on doing the right thing so I thought it would be fine because I want the same thing that they were going to want from me. I had appointments with them for months and they did some home visits and we had meetings where all the other services I was involved with would come. Everyone who had anything to do with me said that I was a really good mum and all the urine tests had been clean right from the start and I was doing pretty well. Then suddenly DoCS wanted me to do some supervised urine tests. I was really annoyed because I’d well and truly proved myself, it’s demeaning and I didn’t understand the need. I explained why I didn’t want to go but they sort of forced me to go. I felt threatened – if I didn’t go they’d take my baby! I felt really angry but I wasn’t rude, I just politely stated my case. I said that there’s no bloody reason to take my baby. That’s child abuse to take a baby off her mother when it’s for no reason, that’s abusive itself. I was really cranky that she started threatening to take Sophie if I dared question what she told me to do. It was just like a battle of the wills which they wanted to win, not about what was the right thing to do. The whole thing was just so unfair, but I actually had to go and they watched me pee. It was just so demeaning and upsetting to have to turn up with the pram with my baby – I’m such a drop-kick mother. It really upset me a lot.

My mum rang DoCS about it and they sort of apologised and organised for my case worker and another lady to do a home visit. It was like my case worker had brought the ‘big guns’ with her. The night before I’d felt really scared because I’d heard a noise outside and Sophie and I ended up sleeping the rest of the night in my mum’s room. The DoCS lady was so sarcastic about me being scared and needing to sleep in my mum’s room. I felt like I was a child and they were looking down on me. They wanted to go into my mother’s room to look at the baby, but I said no, because she was asleep and my mother hates anyone going into her room – it’s her private space. They started saying threatening me again to take my baby if I didn’t let them go in there. The cranky lady said that they could remove the baby for that and stuff like that, so I went and got Sophie. I’d already complained about the threat to take Sophie if I didn’t do the urine test and then they were threatening me again!

They ended up closing the case because of the support I got from Robyn and the others. It made DoCS stop and think, maybe she is OK. Robyn and my case worker at the Methadone clinic wrote letters saying that there was no need to keep my case open as it was getting a bit much. So they did close it which was good, but it took all my other case workers to tell them; it got a bit silly. Lou from youth
housing, and Robyn and Sandra have given me a lot of support and are really nice people. People who accepting and less judgemental and not like morality police trying to teach people a lesson are the ones who have been a big help to me. I haven’t seen Robyn for a while now as things are going along fine, but I plan to make an appointment to see her at the clinic soon.