‘Standing alongside’ and in solidarity with Traveller women: minority ethnic women’s narratives of racialized obstetric violence

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Declaration

I, the Candidate, certify that this thesis is all my own work and that I have not obtained a degree in this University or elsewhere on the basis of any of this work.

Signature: __________________________________

Date: 01/08/19

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List of abbreviations

AIMSI	Association for Improvements in the Maternity Services Ireland
AITHS	All Ireland Traveller Health Study
BNIM	Biographic narrative interpretive method
CAT	Committee Against Torture (UN)
CEDAW	Committee on the Elimination of Discrimination Against Women (UN)
CERD	Committee on the Elimination of Racial Discrimination (UN)
CHWs	Traveller Community Health Workers
CoE	Council of Europe
CRC	Convention on the Rights of the Child
CSDH (WHO)	Commission on Social Determinants of Health
DCYA	Department of Children and Youth Affairs
DES	Department of Educations and Skills
DHPLG	Department of Housing Planning and Local Government
DJE	Department of Justice and Equality
DoH	Department of Health
DoHC	Department of Health and Children
ECRI	European Commission against Racism and Intolerance
ENAR	European Network Against Racism
ERRC	European Roma Rights Centre
ERTHN	Eastern Regional Traveller Health Network
FCPNM	Framework Convention for the Protection of National Minorities
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICCPR	International Covenant on Civil and Political Rights
IFPA	Irish Family Planning Association
IHREC	Irish Human Rights and Equality Commission
NTHN	National Traveller Health Network
NTRIS	National Traveller and Roma Inclusion Strategy
PHCTPs/PHCPs	Primary Health Care for Travellers Project
TCWG	Traveller Consanguinity Working Group
THAC	Traveller Health Advisory Committee
THAF	Traveller Health Advisory Forum
THU	Traveller Health Unit
UN HRC	United Nations Human Rights Committee
VCR	Voice-centred relational method
WHO	World Health Organization

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Abstract

This study is an exploration of Traveller women's experience of pregnancy loss in Ireland. It examines the individual, interpersonal and structural factors which mediate Traveller women's experience. Through the utilisation of a participant structured interview influenced by the biographical narrative interpretive method (BNIM), this study has explored the pregnancy loss experience of eleven Traveller women spanning over a 30-year period. Using the voice-centred relational (VCR) method of analysis, this study suggests that the broader structural landscape of discrimination, racism, sexism, marginalisation and inequality is integral to understanding Traveller women's lived experiences, including pregnancy loss. It highlights Traveller women's experiences of disrespectful and abusive treatment by health services during and after pregnancy loss; this includes neglect, abandonment, non-consented treatment and discrimination. It argues that Traveller women's experiences of pregnancy loss are shaped and pronounced by gendered racism and suggests that these experiences are racialized obstetric violence on the basis of gender and ethnicity.

Chapter 1

Introduction

1.1 Background and context

Representing less than 1% of the nation's population, Irish Travellers are a minority ethnic group, indigenous to the island of Ireland, maintaining a shared history, language, traditions and culture (DTEDG, 1992; O'Connell, 1996, 1997). It is only quite recently that the Irish State formally acknowledged Traveller ethnicity, despite calls from Traveller organisations and exhaustive recommendations from several UN treaty-monitoring bodies, European institutions, and equality and human rights bodies.[1] Travellers have been recognised as one of the most marginalised and disadvantaged groups in Ireland, experiencing structural and systematic discrimination, active prejudice and racism (O'Connell, 1996, 1997). This has been observed both nationally and internationally by human rights organisations and monitoring bodies. Research to date on discrimination in Ireland is consistent in measuring the prevalence of anti-Traveller racism and discrimination; it also complements existing international research more widely on the discrimination experienced by Roma[2] throughout Europe. This is reflected in a national survey conducted by MacGréil (2010) which gauged the perceptions of Travellers by the majority population:

- 40% of respondents were unwilling to employ a Traveller;
- 79.6% were reluctant to purchase a house next to a Traveller; and
- 18.2% would deny Irish citizenship to Travellers.

This was followed by the most recent analysis on discrimination which found that Travellers are almost ten times more likely than those in the majority population to experience discrimination in accessing accommodation. This was also the case in terms of seeking work; this is clearly demonstrated in Census 2016, which reports the Traveller unemployment rate at 80.2% (CSO, 2017). McGinnity et al. (2017) also found that Travellers are over twenty-two times more likely to experience discrimination in Ireland in private services,[3] specifically in

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[1] This includes: ECRI (1997, 2002, 2007, 2013); CESCR (2002, 2015); FCPNM (2003, 2006, 2013); CEDAW (2005, 2017); CERD (2005, 2011); CRC (2006, 2016); CCPR (2014); the Irish Human Rights and Equality Commission, two Joint Oireachtas Committees on Justice (Equality/Defence and Equality) (Houses of the Oireachtas 2014, 2017a); and UN Member State recommendations during the Universal Periodic Review (UPR) process in 2011 and 2015.

[2] The term 'Roma' used at the Council of Europe refers to Roma, Sinti, Kale and related groups in Europe, including Irish Travellers and the Eastern groups (Dom and Lom), and covers the wide diversity of the groups concerned, including persons who identify themselves as 'gypsies'.

[3] This includes shops, pubs, restaurants, banks and accommodation.

shops, pubs and restaurants, where Travellers are thirty-eight times more likely to experience discrimination. Travellers are also almost ten times more likely to report discrimination in access to accommodation. Traveller experiences of discrimination extends beyond private spaces with the *All Ireland Traveller Health Study*[4] (AITHS) (AITHS Team, 2010a) identifying Travellers' high levels of self-reported discrimination in the areas of education, accommodation, employment and in accessing health services.[5]

The AITHS is the most comprehensive analysis of Traveller health undertaken in Ireland to date, yielding an unprecedented 80% response rate amongst Travellers throughout the island of Ireland due its innovative peer-led methodological approach[6] (AITHS Team, 2010a: 32). Adding to previous Traveller health studies,[7] the AITHS study found the current state of Traveller health was comparable with the levels found in the majority population of the 1940s and 1960s, leading the authors to conclude:

> At all ages and for all causes of death, Travellers experience a higher mortality than the general population. The problem is endemic and complex and will not be solved in the short term without considering the wider contextual issues. The fact that an identifiable disadvantaged group in our society is living with the mortality experience of previous generations 50–70 years ago cannot be ignored. The fact that the gap between Traveller mortality and that in the general population has widened in the past 20 years shows that comprehensive approaches to address this situation are required and are indeed vital. [AITHS Team, 2010a: 13]

The statistics indicate that Travellers are not benefitting from advances in health compared to those in the majority population, despite having formal access to the same health services. Instead, the AITHS confirmed that while health services were available to Travellers, services were perceived as inadequate and substandard by Travellers, resulting in lower engagement and poor health outcomes (AITHS Team, 2010a). This includes:

- discrimination and racism (both at individual and institutional levels);
- lack of trust in health care providers and inappropriate service provision; and
- lack of engagement from service providers with Travellers and Traveller organisations.

This was supported by 66.7% of service providers who agreed that discrimination against

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[4] This study draws on all three of the AITHS technical reports. The first report, provides an overview of the findings based on thematic areas and key recommendations; the second report focuses specifically on the birth cohort dimension of the study and information in relation to Travellers in institutions; and the third report presents the qualitative research including from health service providers and Travellers.

[5] According to the AITHS (2010a: 74): 62.1% of Travellers reported discrimination at school; 56% of Travellers reported experiencing discrimination getting accommodation; 55% of Travellers reported experiencing discrimination reported discrimination in seeking work; and over 40% of Travellers reported experiencing discrimination in accessing health services

[6] 450 Traveller Peer Researchers and 90 study coordinators, who were working in Primary Healthcare for Traveller Projects (PHCTPs) and Traveller organisations were trained as local data collectors using the laptop computers. Peer Researchers identified and recruited 10,618 Traveller families for the study. See AITHS (2010a:84) for further information.

[7] See Rottman et al., 1986; Barry et al., 1989

Travellers occurs sometimes in their use of health services, resulting in substandard treatment of Travellers, with one service provider observing:

> It does exist […] there is that sentiment that Travellers are less deserving, hence give them substandard services. [AITHS Team, 2010c: 84]

The issue of racism was also identified as a key issue, with a service provider suggesting, "racism as one of factors, but it won't be said officially as they [institution] will be in trouble" (AITHS Team, 2010c: 84). According to Fay (2018), eight years since the AITHS, Traveller health inequalities remain the same, and in some cases, due to improvements in the overall national population, Traveller health disparities have widened. The AITHS provided a strong roadmap to address Traveller health inequalities, given its evidence base and clear policy recommendations. However, the findings have largely been met with inaction and disinvestment by the State, despite European obligations (see Chapter 3) and prompts from a number of European institutions and UN treaty-monitoring bodies.

1.2 Traveller women: perinatal health outcomes

This study focuses specifically on Traveller women's perinatal health. Similar to other indigenous and minority ethnic women, in terms of an overall demographic profile, Traveller women's perinatal outcomes remain exceptionally poor. Again, despite having formal access to maternity and infant care services,[8] Traveller women have a higher rate of maternal morbidity (Manning et al., 2015; Manning et al., 2016; Manning et al., 2018) and infant mortality, including higher rates of miscarriage,[9] stillbirth[10] and neonatal death (See Appendices III-VII). As the AITHS reports:

- Infant mortality rate for Travellers is 3.7 times the national rate and 2.8 times the EU average
- Neonatal mortality rate[11] for Travellers is almost 2 times the EU average
- Post-neonatal mortality[12] rate for Travellers is 4.5 times the EU average

The Infant Mortality Rate (IMR), defined as the number of deaths in children under one year of age per 1,000 live births in the same year has been traditionally used as an instructive indicator of a population's overall health and development (Krieger, 2000a; 2000b). According

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[8] The AITHS found that while Travellers are more likely to present later in pregnancy than other group, almost all Traveller women accessed antenatal care before birth with 98% booked in for delivery and all (100%) were delivered in a hospital (AITHS Team, 2010b)

[9] Traveller women experienced a higher rate (34.8%) of miscarriage (within 24 weeks) as compared to women in the majority population (28%) (AITHS Team, 2010b).

[10] Stillbirth is three times higher for Traveller women when compared to women in the majority population (AITHS Team, 2010b).

[11] The neonatal mortality rate is defined as rate of infant deaths under 28 days from birth per 1,000 live births (AITHS Team, 2010b).

[12] The post-neonatal mortality rate is defined as the rate of infant deaths after 28 days to first year of life per 1,000 live births (AITHS Team, 2010b).

to the AITHS (AITHS Team, 2010b) when compared to other minority ethnic groups, the Irish Traveller infant mortality rate is one of the highest at 12 per 1,000 live births. Further, when the infant mortality rate ratio between minority ethnic groups and the majority populations is calculated, Irish Travellers have the largest rate ratio at 3.7 compared to other minority groups. It is similar to the Northern Territory Australian Aboriginals and Torres Strait Islanders (See Appendices VI-VII).

The significance of a country's infant mortality rate lies in the, "association between the causes of infant mortality and other factors that are likely to influence the health status of whole populations" (Reidpath and Allotry, 2003: 344), including economic development, general living conditions, social well-being and rates of illness. It also reflects the broader social, historical and structural context, which shapes health outcomes including racism, discrimination and sexism. As Haldeman (2005) posits, the infant mortality rate:

> …reveals more than the number of infant deaths, rather it exposes the conditions, experiences and social mores that do not support healthy mothers, fathers and families in a given society. [Haldeman 2005: 38]

Similar to the overall experience of Travellers in engaging with health services in Ireland, Traveller women's experience with maternity services is mediated by discrimination and racism; a lack of trust; a lack of engagement from service providers; and a lack of accessible health information and advice (Reid, 2005; Reid and Taylor, 2007; AITHS Team, 2010a). However, beyond service level provision, Traveller women remain absent from national policy frameworks in relation to maternal health, including the *National Maternity Strategy 2016-2026* (Department of Health, 2016). This, despite (1) having the poorest perinatal outcomes in the country; and (2) being some of the most frequent users of the Irish maternity services as a result of rates of pregnancy.[13] The omission of Traveller women in policy has resulted in their exclusion in mainstream services as they are rendered invisible and their particular needs are overlooked.

1.3 Pregnancy loss

While not experientially analogous in any way, feminist scholars[14] have used the umbrella term *pregnancy loss* to refer women's perinatal loss, that is, experiences of infertility, miscarriage,

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[13] According to the *All Ireland Traveller Health Study* (2010a, 2010b), 98% of Traveller women accessed antenatal care prior to giving birth, with 100% of all Traveller infants delivered in hospital.

[14] See e.g.,Lovell (1983); Cecil (1996a, 1996b); McCreight (2001, 2004, 2008); Haldeman (2005); Layne (2006, 2003); Letherby (1993); McNiven (2014, 2016);

abortion, stillbirth, perinatal death and infant death. This study adopts a similar perspective reflecting Traveller women's subjectivities of such loss and the "fluidity of definitions, understandings and experiences" (Earle et al., 2012: 1). This broad approach ensures that the inquiry is not hierarchical as it does not provide a taxonomy of experiences of loss in a way that, "some might be seen as more 'serious' or more 'traumatic' than others" (2). This study includes and reflects on a variety of pregnancy losses including miscarriage; stillbirth;[15] early[16] and late[17] neonatal death.

It is estimated 30–40% of all pregnancies end in loss (Michels and Tiu, 2007; Sapra et al., 2017). According to the World Health Organization (2018a), there are approximately 2.6 million stillbirths worldwide each year. While it is difficult to ascertain the incidence of miscarriage globally given the substantial variability in the definition of miscarriage[18] and the lack of systematically recorded data, estimates suggest that 10–20% of all pregnant women will experience a miscarriage, with the majority of miscarriages occurring in the first trimester (Institute of Obstetricians and Gynaecologists et al., 2010; Cohain et al., 2017; NICE, 2018). In Ireland, pregnancy loss, in the form of miscarriage or stillbirth, occurs in approximately 20–25% of all pregnancies (UCC Department of Obstetrics and Gynaecology, 2018). Despite the fact that "pregnancy [loss] is a much more common experience for women than birth" (Ivry, 2009: 6), "a veil of silence" continues to surround the substantive topic both academically and in public discourse (Layne, 2003, 2009; Rowlands and Lee, 2010; Zucker, 2014; McNiven, 2016; Peel and Cain, 2016; Ui Dhubhgain, 2018).

There have been some developments over the past decade with a number of high profile individuals such as Michelle Obama, Beyoncé and Priscilla Chan publicly disclosing their pregnancy loss experiences (Bologna, 2015; Pavia, 2018). In addition to periodical news coverage,[19] a number of social media campaigns such as the Twitter #IHadAMiscarriage campaign launched in the U.S. in 2014, have also provided new platforms for public discussion on pregnancy loss as they seek to "de-silence, de-stigmatize, and de-shame" women's

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[15] This refers to the death of a baby who weighs at least 500 grams or has a gestational age of at least 24 weeks. If a baby dies before 24 completed weeks and weighs less than 500 grams, it is considered by medical professionals to be a late miscarriage (HSE, 2018a: para 1).

[16] This refers to the death of an infant less than one week after birth

[17] This refers to the death of an infant more than one week after birth

[18] This includes pregnancy loss prior to viability, the loss of a foetus weighing less than 500 grams (Institute of Obstetricians and Gynaecologists et al., 2010) the loss of an embryo or foetus at 24 weeks' gestation or less (Institute of Obstetricians and Gynaecologists et al., 2010) or at 28 weeks' gestation or less (WHO, 2018a).

[19] See for example, US outlets such as: the *New York Times* (Zucker, 2014); *Huffington Post* (Bologna, 2015); *The Washington Post* (Martinelli, 2016); and Irish news outlets such as: the *Irish Times* (O'Morain, 2018; Ui Dhubhgain, 2018) and a number of other outlets. Periodical cover tends to coalesce with particular days marking infant/pregnancy loss (e.g. International Pregnancy and Infant Loss Remembrance Day).

experiences (Zucker, 2014; Bodgas, 2017: para 2; Nsoesie and Cesare, 2017). Similarly, the Irish Twitter campaign, #maternityire launched in 2013 provided a public forum for women to share their experiences with Irish maternity services, including experiences of pregnancy loss. However, it was the death of Savita Halappanavar in 2012 due to severe sepsis following a miscarriage[20] which provided the impetus for a renewed national conversation on pregnancy loss, eventually leading to a referendum on the Eighth Amendment of the Constitution of Ireland in 2018 (Reid, 1992; Smyth, 1992a, 1992b; Berer, 2013; Quilty et al., 2015). The Halappanavar case, alongside a number of other high profile cases and inquiries into maternal[21] and perinatal deaths[22] in Irish maternity units have created the conditions for a new dialogue on pregnancy loss, and in particular, the need for changes in legislative, policy and service provision (Kennedy, 2002, 2004, 2012; HSE, 2013a; HIQA, 2015; Murphy-Lawless, 2015). Yet, despite these shifts, pregnancy loss remains a "taboo subject" which is "rarely spoken or talked about," with social responses of silence adding to feelings of isolation and shame for many who experience loss (Layne, 2003; Simmons et al., 2006; Rowlands and Lee, 2010; Flenady et al., 2016; McNiven, 2016; The Lancet, 2016; Ui Dhubhgain, 2018: para 1).

Furthermore, in terms of academic scholarship, and notwithstanding the global body of midwifery-focused and medically-informed research on pregnancy loss, the substantive research area remains relatively under-examined amongst social scientists. Where social science research[23] exists, it has focused on the individual and interpersonal dimensions of loss, often omitting a broader structural analysis beyond health systems and institutions. With the exception of contributions from social work,[24] only a handful of social science scholars in Ireland have adopted pregnancy loss as a meaningful topic of inquiry (Cecil, 1994a, 1994b, 1996a, 1996b; McCreight, 2001, 2004, 2007, 2008; Garattini, 2007; Earle et al., 2008). Feminist researchers such as Layne (2006a) and others[25] have called on scholars to contribute to a new discussion of pregnancy loss shifting it from a private space of "shame" to a public space of "solidarity," acknowledging the "frequency and import[ance] of such events in

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[20] On 21 October 2012, Savita Halappanavar was admitted to University College Hospital Galway for management of "an inevitable/impending pregnancy loss" (HSE, 2013c: 21). Despite repeated requests for an abortion, Halappanavar was refused by the clinical team on the basis that the foetal heart was still beating. Halapanavar died one week later due to sepsis (HIQA, 2013; Hollaned, 2013; HSE, 2013c; Quilty et al., 2015). See Chapter 2, Section 2.7 for further discussion.

[21] This includes Malak Thawley, Tania McCabe, Jennifer Crean, Nora Hyland, Dhara Kivlehan, Bimbo Onanuga and Savita Halappanavar (HSE, 2008; HIQA, 2013; Quilty et al., 2015).

[22] This refers to perinatal deaths at Midland Regional Hospital, Portlaoise. See Chapter 2 for further discussion.

[23] For example, sociology, theology, philosophy, anthropology and geography.

[24] See e.g., Brosig et al., (2007); Cacciatore and Bushfield (2007); Bryant et al. (2010); McLean and Flynn (2012); Mukherjee et al. (2013); Mulvihill and Walsh (2013)

[25] See e.g.,Cosgrove (2004); Van der Sijpt (2007, 2010, 2017); Smith (2013); Craven and Peel (2016); Peel and Cain (2014); McNiven (2014, 2016).

women's lives and create a woman-centred discourse of pregnancy loss" (239). There has been a growing recognition amongst feminists to ensure an intersectional lens is applied in this regard and that minority ethnic women's voices are included in this new discussion, particularly given clear health disparities (Madden, 1994; Cecil, 1996a; Van, 2001; Van and Meleis, 2003a, 2003b; Haws, 2009, 2011; Bryant et al., 2010; Whitaker, 2010; Mukherjee et al., 2013; Paisley-Cleveland, 2013; Chen et al., 2015). A number of scholars in North America, Australia and New Zealand[26] have responded directly to this critique by focusing specifically on indigenous and minority ethnic women's experiences of pregnancy loss. However, notwithstanding the inclusion of Traveller women's experiences in the works of Kennedy (2004; 2002), no research to date has focused on Traveller women's experiences of pregnancy loss. Where it has featured in Traveller related research (see e.g., Gmelch, 1975; Okley, 1998[1983]; Helleiner, 2000[1961]) it has been given little prominence in the overall narratives or stories presented.

1.4 Background to the study

This study builds on ethnographic research conducted in 2012 as part of a master's dissertation in anthropology. I had just returned to Ireland after living in the United States for seven years and had become engaged with Irish feminist groups that focused on reproductive rights. At the time, Ireland was undergoing its first UN Universal Period Review[27] and local consultations were facilitated by the Department of Justice, Equality and Defence. During the consultation, a Traveller group highlighted findings from the AITHS, including statistics related to Traveller women and perinatal health. The outcomes were stark and it was at this juncture that I questioned the serious lack of attention and/or analysis within the feminist movement and wider discourse on women's reproductive rights and justice. Drawing on my experience of living in the United States and volunteering with a non-profit health family planning clinic, I could see clear parallels in terms of health outcomes amongst indigenous women, minority ethnic women and Traveller women. My master's dissertation provided scope to explore this further, and as a result, I contacted Traveller organisations with a proposal to conduct ethnographic research, using participant observation and in-depth interviews to explore Traveller women's experiences of pregnancy and motherhood in Ireland. After some time, two

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[26] See e.g., Liamputtong (2000); Rice (2000); Van (2001); Abboud and Liamputtong (2005); Kavanaugh and Hershberger (2005); McManus et al. (2010); Le Grice and Braun (2017); Van and Meleis (2003b)

[27] The Universal Periodic Review (UPR) is a unique peer-led review of human rights records of all UN Member States. According to the United Nations Human Rights Council (2018), the UPR is a "State-driven process, under the auspices of the Human Rights Council, which provides the opportunity for each State to declare what actions they have taken to improve the human rights situations in their countries and to fulfil their human rights obligations" (para 1). The overall aim of the UPR is to improve the human rights situation in Member State and address human rights violations.

local Traveller organisations (one rural and one urban) indicated that they were interested in the research and we began to work together.

Using a similar methodology to the AITHS, I worked with Traveller Community Health Workers in two Primary Health Care for Travellers Projects[28] (PHCTPs), and together, we carried out in-depth interviews with seventy-five Traveller women over a 12-month period. One of the most striking findings from the research was the prevalence of pregnancy loss, with over a half of Traveller women disclosing they had experience at least one miscarriage over the course of their reproductive lives (Kavanagh, 2013). This is twice the projected national rate and higher than reported in the AITHS (2010b). Moreover, over one-sixth of Traveller women disclosed that they had experienced an infant death. These experiences were reported as significant life events for Traveller women which had a considerable impact on women's overall health and well-being and in particular informed how Traveller women navigated subsequent pregnancies. The findings of the research were presented to the partner organisations and resulted in a direct effect on the work that they undertook with Traveller women in their respective areas. The research would not have been possible without working in partnership with the PHCTPs both in terms of securing Traveller women's participation, in the research analysis and final write-up. The research also demonstrated the value of working in partnership with Traveller organisations to inform work on a local basis.

However, I was conscious that the structural issues identified in the research, coupled with findings from the AITHS (2010a, 2010b) required consideration beyond a local context and action from policy makers if real, transformative social change were to be achieved. In addition, it was also necessary to explore the topic of pregnancy loss in greater depth in order to develop an understanding of the factors contributing to the experiences of Traveller women in this regard. I recognised that further ethnographic research would not be the most appropriate methodological approach to this study and instead, sought a new department that could support the development of further research in this regard as well as the particular kind of narrative research I sought to do. The Department of Applied Social Studies at Maynooth University has

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[28] Primary Health Care for Travellers Projects (PHCTPs) are peer-led projects which use a community development approach to address Traveller health inequalities. PHCTPs train and employ Traveller Community Health Workers to identify and develop joint projects and initiatives with local health services. Using a social determinants approach to health, Traveller Community Health Workers undertake health advocacy in a range of health arenas, for example, perinatal health, health education, infant health, mental health, accommodation and environmental health issues, immunization and health alerts, addiction, etc. For further discussion see Section 1.6.1.

a strong reputation for commitment to and expertise in the areas of human rights, equality and social justice as evidenced by its mission statement:

> To promote human rights, social justice and equality, nationally and internationally, through excellence and innovation in education, research and public engagement that contribute to the development of the social professions and applied social sciences. [DAPSS, 2018: para 1]

This expertise is based on practice in these areas as well as teaching, research and public contributions locally, regionally, nationally and globally. It has played a critical role in the development of studies on racism and inclusion, human rights and discrimination in Ireland. This has always been done in partnership with communities, including Travellers and other minority ethnic groups, underscoring the importance of the mission statement alongside the key community principles which underpins all of the department's work. Particularly useful for this research was the longstanding relationships which the department had with Traveller organisations, including Pavee Point Traveller and Roma Centre ('hereafter Pavee Point') who have collaborated with the department on a number of projects over the years. My supervisor was particularly suitable for this project given her substantial experience as a community development worker working in solidarity with Travellers and other groups. This meant that she had an in-depth practitioner-based knowledge of the field which was invaluable in supporting a different approach to the research than that in my master's dissertation. Therefore, the department offered this research suitable expertise and supports at a number of levels.

After commencing my doctoral studies in 2014, I was encouraged to enrol in an internship module offered by the Department and to seek a placement with Pavee Point given their longstanding work in promoting Traveller and Roma human rights both within Ireland and in international arenas. Of particular relevance was their expertise in addressing Traveller health inequalities; this included establishing the very first Traveller Primary Health Care Project in Ireland and overseeing the ground-breaking AITHS. The purpose of the internship was to develop the necessary relationships, knowledge and skills required to carry out this research. To pass the module, students must complete a six to eight-week internship. I exceeded this requirement and completed a part-time twelve-month internship and was subsequently offered a paid position in research, policy and analysis. This experience provided a strong basis to further develop my knowledge of the field and contributed significantly to the methodological approach to the research and informing the overall analysis. Given the strong relationship with Pavee Point, we developed an application for the Irish Research Council Employment Based Postgraduate Programme. This Programme provides a unique opportunity to support the development of collaborative research between early career students, their university and an employment partner. We were successful with the application and the award was granted for the remainder of the PhD.

This research would not have been possible without the support of Pavee Point, alongside the Irish Research Council. This investment in developing a strong relationship with the organisation was formative as it enhanced my knowledge of the policy landscape in relation to Travellers and Roma both nationally and internationally. It challenged my approach to research, ensuring that community development principles[29] underpinned the work and analysis, connecting the "micro-narratives and macro-level structures and processes" (Mauthner and Doucet, 2003). Most importantly, it created the necessary conditions to work in solidarity with Travellers and Roma. Through this partnership, we could use research as a tool to challenge racism and discrimination and promote Traveller and Roma equality and human rights. This has been an ongoing process. Throughout the past four years, this study has informed Pavee Point's broader policy work, but more specifically its perinatal health work including the development of *Pavee Mothers*, a national Traveller perinatal health initiative (see Chapter 8). This demonstrates the added value of research and it is only by working in active partnership with Traveller women and Pavee Point that a practical application of the research was possible.

1.5 Pavee Point Traveller and Roma Centre

Established in 1985, Pavee Point is recognised both nationally and internationally as a leading human rights organisation working for the development, implementation and monitoring of policies and initiatives to promote equality for Traveller and Roma communities (DTEDG, 1992; O'Connell, 1996, 1997). As Fay (2018) notes:

> The starting point of our work was based on two essential premises which are: (1) Travellers themselves must be involved in the most important decisions that affect their lives; and (2) racism and inadequacy of policies of inclusion are at the root cause of Traveller inequalities. Pavee Point were the first organisation to recognise the importance of and campaign for State acknowledgement of Traveller ethnicity.[30] Community development, with its associated principles of social justice, solidarity, equality and human rights; and an approach that involves participation, empowerment and collective action has been fundamental in informing our work with Travellers. [Fay, 2018: para 1]

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[29] Community development and community work are used interchangeably in this study. Adapting their definition from Pobal (1999), Community Work Ireland (2016: 5) define community work as, "a developmental activity comprised of both a task and a process. The task is social change to achieve equality, social justice and human rights, and the process is the application of principles of participation, empowerment and collective decision making in a structured and co-ordinated way."

[30] See DTEDG (1992)

The organisation is comprised of Travellers, Roma and members of the majority population working in partnership to address the needs of Travellers and Roma as minority ethnic groups experiencing discrimination, racism, exclusion and marginalisation (DTEDG, 1992; O'Connell, 1996; Fay, 2018). Pavee Point undertakes specific programmes including violence against women, communications, drug and alcohol, Roma and health. The health programme is one of the largest in Pavee Point and includes the Primary Health Care for Travellers Project (PHCTP), men's health, drugs and alcohol and mental health. Perinatal health has been added as a key focus of work as a result of this study.

1.6 Pavee Point's health work: local, regional and national focus

Drawing on a human rights framework, including the right to health,[31] Pavee Point's health work is underpinned by a social determinants of health analysis which presupposes that health outcomes are shaped by micro, meso and macro level processes, including racism and discrimination (Dahlgren and Whitehead, 1991). The health work is located within the existing Traveller health infrastructure and has a national, regional and local focus (see Appendix II) all of which have informed and contributed to the development of this study.

1.6.1 Local work

On a local level, the organisation works in partnership with the Health Service Executive (HSE) through its PHCTP. The Pavee Point PHCTP dates back over 20 years following a commitment in the *Shaping a Healthier Future: A Strategy for Effective Healthcare in the 1990's* (Department of Health, 1994) which committed to implementing a "special programme […] to address the particular health needs of the travelling community (60). Using a Primary Health Care model[32] which is rooted in a commitment to social justice, equity and the right to health

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[31] The right to health was first articulated in the 1946 Constitution of the World Health Organization (WHO), which defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity […] the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (para 2-3).

[32] The Primary Health Care (PHC) concept was proposed at the joint WHO/UNICEF conference in Alma-Ata in 1978 which acknowledged the need for significant reform in conventional health systems, as it notes:

> Primary Health Care (PHC) is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community, through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It is the first level of contact of individuals, the family and community with the national system, bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process [WHO, 1978: para 5]

PHC is as a, "whole-of-society approach to health that aims equitably to maximize the level and distribution of health and well-being by focusing on people's needs and preferences (both as individuals and communities) as early as possible along the continuum from health

(WHO, 1978), Pavee Point submitted a proposal to the Eastern Health Board and the PHCTP was established as a pilot initiative in 1994. This project radically shifted the approach to Traveller health as it moved away from the previous charity-based model to a peer-led, community development approach. According to Missie Collins:

> I was the first one to approach the Health Board with Ronnie Fay. They said it's not going to work – Travellers working with Travellers. They said we can't read or write. But, I said to myself, you can't tell me that because I know our needs. We kept working away. [Fay and McCabe, 2015: 52]

Collins, alongside seven other Traveller women who were employed as Traveller Community Health Workers (CHWs) were the first to carry out a baseline needs assessment in two Traveller sites in North Dublin. The research provided critical information on the needs of Travellers in the area and was used to develop strategies to target Traveller health inequalities. This pilot was acknowledged in the *Report of the Task Force on the Travelling Community* (Government of Ireland, 1995) and the *National Traveller Health Strategy* (Department of Health and Children, 2002) both of which strongly endorsed the work of the PHCTP and recommended its replication throughout the country. There are approximately twenty-five PHCTPs nationally, with these projects employing primarily Traveller women as Traveller Community Health Workers (CHWs).

The Pavee Point PHCTP is comprised of seventeen CHWs who undertake health advocacy in a range of health arenas[33] primarily though outreach work with approximately 300 Traveller families in the Dublin North City and County. This includes collecting a range of health data which are collated by Pavee Point through the Eastern Region Traveller Health Unit and reported on a regional basis to the HSE. This data is used to benchmark Traveller health through national Traveller Health Key Performance Indicators.[34] Alongside this work, CHWs engage with mainstream health services and other state agencies to provide professional development training in anti-racism and discrimination. The aims of the PHCTP (Fay, 2018) are to:

- establish Primary Health Care as a model of good practice to address Travellers' health;
- develop the skills of Travellers in providing health services within the community;
- work collaboratively and assist with communication between Travellers and health service providers; and
- highlight gaps in health service delivery to Travellers and work towards reducing inequalities that exist in established services.

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promotion and disease prevention to treatment, rehabilitation and palliative care, and as close as feasible to people's everyday environment" (WHO, 2018b: viii).

[33] For example: mental health, health education; child and infant health; immunisation and health alerts; addiction; diet and exercise; health and well-being; women's health; men's health; and social determinants work including accommodation and environmental health issues.

[34] This data is included in the HSE Primary Care Division - Social Inclusion Key Performance Indicator Metadata which is published on an annual basis.

Underpinned by a community development approach which emphasises participation, empowerment and collective action, the PHCTP encourages intersectoral collaboration with health services and other state agencies within the broad framework of a social determinants approach as discussed above. This model has been identified as an effective approach in bridging the gap for Travellers' engagement with mainstream health services, as a "community experiencing high health inequalities and a health service unable to reach and engage that community effectively in health service provision" (Fay et al., 2017: 3). A number of countries[35] have adopted this model as a mechanism to engage marginalised communities, particularly Indigenous and minority ethnic groups in mainstream health provision (Keyes and McCabe, 2013; Harfield et al., 2018). In Ireland, the success of the PHCTP is evidenced in the results of the AITHS (AITHS Team, 2010a), which reported that Traveller women had a higher uptake in health screening services when compared to women in the majority population. For example:

- 25% of Traveller women had a breast screening; compared to 13% of women in the majority population; and
- 23% of Traveller women had cervical smear test; compared to 12% women in the majority population.

The AITHS also found that the majority (83%) of Travellers received health information and advice from Traveller organisations and PHCTPs. While the AITHS identified PHCTPs as a vital mechanism for supporting Travellers' access to health services and information, PHCTPs have been instrumental in supporting other State agencies to engage with Travellers. For example, immediately following a tragic fire on a Traveller site in 2015, CHWs played a central role in facilitating the National Traveller Fire Safety audit, providing on-site fire training to families and liaising with the local authorities to ensure that fire and carbon monoxide alarms were delivered to families (Fay et al., 2017).

1.6.2 Regional work

At regional level, Pavee Point coordinates and provides technical assistance to the Traveller Health Unit (THU) in the Eastern Region. Traveller Health Units were established following the *Report of the Task Force on the Travelling Community* (Government of Ireland, 1995),

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[35] For example, the United States, Australia, Canada, New Zealand, Cuba, India and Brazil (Vlassoff et al., 2010; Harfield et al., 2018; WHO, 2018b)

which sought an effective mechanism to ensure Traveller health issues were mainstreamed into general health policy and service provision. The Task Force recommended that each health board establish a THU comprised of service providers, Travellers and Traveller organisations to:

- Monitor the delivery of health services to Travellers and to set regional targets against which performance may be measured;
- Ensure that Traveller health is given due prominence on the agenda of the HSE;
- Ensure coordination and liaison between the HSE and other statutory and voluntary bodies, in relation to the health situation of Travellers;
- Collect data on Traveller health and utilisation of health services;
- Ensure the appropriate training of health service providers in terms of their understanding of and relationship with Travellers; and
- Support the development of Traveller-specific services, either directly by the HSE or indirectly through funding appropriate voluntary organisations.

THUs were understood as an effective mechanism to address Traveller health inequalities and as the foundation in which health services could be delivered to Travellers at regional levels. The Task Force recommendation was implemented as part of the *National Traveller Health Strategy* (Department of Health and Children, 2002) which reiterated the need for the THUs and committed funding to enable THUs to implement the strategy, progress new health initiatives and resource Traveller groups to participate effectively in the THUs (Kavanagh, 2018). The Eastern Region THU is one of eight THUs across the country. It is the biggest THU in the region covering three Community Health Care Organisations (CHOs)[36] and nine PHCTPs[37] (see Appendix II), working with over 8,200[38] Travellers or 26% of the entire Traveller population in Ireland.

1.6.3 National work

At national level, Pavee Point resources the National Traveller Health Network which is a national forum for all the Traveller PHCTPs in the country. Pavee Point also represents Travellers on a number of national committees including the National Traveller Health Advisory Forum (THAF), which was established by the HSE to oversee national implementation, monitoring and evaluation of health services for Travellers. This was complimented by the National Traveller Health Advisory Committee (THAC) which was

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[36] Community health care services are the broad range of services delivered by the HSE and funded agencies outside of acute hospital system and include primary care, social care, mental health, and health and well-being services (HSE, 2018b). Community Health care Organisations (CHOs) are responsible for the delivery of these services. There are a total of nine CHOs nationally. The Eastern Region THU works across Area 6: Wicklow, Dun Laoghaire, Dublin South East; Area 7: Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West; and Area 9: Dublin North, Dublin North Central, Dublin North West.

[37] In addition to the nine projects, the THU includes a specialist Traveller health initiative.

[38] Figure according to Quarter 2 2018, Traveller KPIs in the Eastern Region.

chaired by the Department of Health and was considered the institutional mechanism that ensured Travellers were included in the development of national policy. However, this committee has not met since 2012, despite calls from Traveller organisations and a number of commitments made by the Minister for Health (see Chapter 4).

1.7 Research question, aims and objectives

The central research question of this study seeks to explore Traveller women's experience of pregnancy loss in Ireland. The aims of the dissertation are twofold; (1) to develop a holistic understanding of Traveller women's experience of pregnancy loss; and (2) to develop an assessment of the voice-centred relational (VCR) method as a response to the research question. The objectives of the research are to explore:

- personal, interpersonal and structural factors that mediate Traveller experiences of pregnancy loss; and
- the voice-centred relational method and its contribution to a new understanding of Traveller women's lived experiences.

1.8 Research design and methods

This study examines Traveller women's experiences of pregnancy loss and seeks to explore the personal, interpersonal and structural factors that mediate those experiences. As minority ethnic women, Traveller women are among the most marginalised and excluded individuals and groups in Ireland due to overlapping systems of oppression and discrimination based on gender, ethnicity and number of other 'axes' (Crenshaw, 1989). This experience is felt at institutional, societal and individual levels, as Fay notes:

> [Traveller women face] triple discrimination -- as Travellers, as women, and as Traveller women […] Traveller women experience patriarchy in the ways that all women do […] they also experience particular forms of abuse as Traveller women, [particularly] when they are brutalized by descriptions in the media. [Fay cited in Reilly, 2006: para 6]

Therefore, from a theoretical perspective, this study is interested in the intersection between gender, ethnicity and power and how this becomes operationalised within institutions and Traveller women's interactions with institutional actors. This study draws on an interpretivist, relational, voice-centred, feminist methodology which understands knowledge socially as situated, taking Traveller women's direct experience as the basis for knowledge. In doing so, it recognises that Traveller women's experiences do not occur within a vacuum, but are embedded in a complex web of larger social and structural relationships (Gilligan, 1993[1982]; Mauthner and Doucet, 1998; Gilligan et al., 2006). Figure 3 provides an overview of the ontological, epistemological and methodological approaches in this study.

The specific methods used are participant structured interviews with eleven Traveller women informed by the biographic narrative interpretive method (BNIM) (Wengraf, 2001); this was complemented using a voice-centred relational method (VCR) analysis approach to analyse interviews. The VCR method is based on a number of 'listenings' of the interview through four structured readings of the transcript. Mauthner and Doucet (1998b, 2003) advocate a flexible approach to the number of readings, contingent on the aims and objectives of the research. This study conducted two initial readings of each transcript; reading (1) relational/reflexively constituted narratives; and (2) ontological narratives. Summaries were also developed for each interview and an overall thematic analysis of the data set as a whole was conducted. Of these, three interviews were analysed to produce detailed case studies and were selected on the basis of difference to each other. This includes the time period in which pregnancy loss occurred, the marital status at the time of pregnancy loss and the geographic location. The detailed case studies, although not included in this dissertation, are presented through I/We/They poems developed from the three case studies. This approach seeks to understand the complexities and nuances within Traveller women's stories on individual, interpersonal and structural levels before women's accounts become mediated by the researcher and "transformed" into theory (Mauthner and Doucet, 2006). The case studies represent the varying analytic angles and implicit ontologies reflected across all Traveller women's narratives and informed the overall collective analysis as presented in Chapter 7.

1.9 Terminology

1.9.1 Traveller

Throughout this work I use "Traveller" and "Irish Traveller" interchangeably to denote the ethnicity of women who participated in this research because these are the terms used by them in voluntarily self-identifying their ethnicity. According to the Equal Status Act "Traveller community" means the:

> Community of people who are commonly called Travellers and who are identified (both by themselves and others) as people with a shared history, culture and traditions including, historically, a nomadic way of life on the island of Ireland. [Government of Ireland, 2015[2000]: 7]

While the European Parliament and of the Council of Europe (2013) use the umbrella term ‘Roma’ to refer to a number of groups[39] such as Roma, Sinti, Kale and related groups in Europe, including Irish Travellers, this study focuses solely on Irish Travellers. ‘Majority population,’ ‘non-Traveller’ and ‘general population’ are used throughout the study to denote the distinction between Travellers and those in the majority population.

1.9.2 Racism

The concept of racism is referenced frequently throughout this study as the basic starting point. Drawing on the definition as set out in the International Convention on the Elimination of All Forms of Racial Discrimination and the works of Essed (1990, 1991, 1996, 2000, 2001, 2013), Jones (2000) and others,[40] this study understands that racism is a specific form of discrimination and exclusion faced by minority ethnic groups. Article 1.1 of the International Convention on the Elimination of All Forms of Racial Discrimination (1965) defines racism as:

> Any distinction, exclusion, restriction or preference based on […] national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment of exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.

Racism is complex and multi-faceted; manifesting both covertly and overtly on individual, interpersonal and institutional levels. According to Macpherson (1999), racism in general terms consists of “conduct or words or practices which disadvantage or advantages people because of their colour, culture, or ethnic origin” (6.2). Racism can manifest in everyday “acts of discrimination, through the barriers and omissions that may be inadvertently established at an institutional level, to acts of threatening behaviour and violence” (Department of Justice, Equality and Law Reform, 2005: 41). This study understands institutional racism as manifesting both in material conditions and in access to power. According to Macpherson (1999), institutional racism is the:

> Collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people [institutional racism] persists because of the failure of the organisation openly and adequately to recognise and address its existence and causes by policy, example and leadership. Without recognition and action to eliminate such racism it can prevail as part of the ethos or culture of the organisation. It is a corrosive disease [Macpherson, 1999: 6.34]

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[39] Including Eastern groups (Dom and Lom)

[40] See e.g.,Hill-Collins (1994) and Crenshaw (1989, 1991)

As Macpherson argues, institutional racism is differential access to goods, services and opportunities of society by minority ethnic groups; it is structural and therefore often subtle and hidden. Chapter 4 provides a focused discussion on intersectionality as a conceptual framework for understanding the ways in which overlapping systems of oppression, including racism and sexism, shape Traveller women's experiences, both on an individual and collective level in Ireland.

1.10 Chapter overview

This was the first of nine chapters in this dissertation. This chapter has served as an introduction to the study. First, it briefly outlined the context, focus and overall aims and objectives of the study. Second, it described the theoretical influences and provided an outline of the methodologies used. Third, it provided an introduction and rationale for the language used throughout the study.

Chapter 2 traces the socio-historical, political and policy contexts in Ireland as they relate to women and pregnancy loss, specifically institutional responses to pregnancy loss, including obstetric settings. It also considers the development of national policy frameworks and practice in relation to pregnancy and loss.

Chapter 3 provides a detailed discussion on Traveller related policy in Ireland, paying particular attention to the policies, practices, and outcomes of institutional racism and discrimination as they relate to Traveller women. This chapter traces the development of Traveller policy and reflects on the key opportunities to promote Traveller human rights and equality.

Chapter 4 provides an empirical and theoretical discussion to contextualise the study and to respond to its overarching aims and objectives. In doing so, it presents a synthesis of research to date on women's experiences of pregnancy loss in Ireland. It also outlines some of the concepts that are relevant to the analysis of the data in this study.

Chapter 5 presents the philosophical and theoretical underpinnings of this research. The chapter provides a detailed discussion of the research paradigm, theoretical framework, addressing both the ontological and epistemological positioning of the study. It outlines the procedures used throughout the study and provides information about the participants, their recruitment and data collection and analysis.

Chapter 6 provides a unique insight into the methods used in this study and the synergistic relationship between a BNIM-influenced interview and a VCR method for analysis. Using three poems from the case studies, this chapter seeks to (1) listen to Traveller women speak for themselves before we speak for them; and (2) illuminate the temporal, relational and structural aspects of Traveller women's narratives.

Chapter 7 responds to the overall research question and first aim of this study, which is to explore the personal, interpersonal and structural factors that mediate Traveller women's experience of pregnancy loss. This chapter presents the collective findings of all interviews, illustrating the relationship between Traveller women's individual and interpersonal experiences of pregnancy loss and the broader intersecting structures in which they are located.

Chapter 8 presents a focused discussion of the findings in relation to the socio-cultural, historical and policy context presented in chapters 2 and 3 in addition to the key literature and concepts presented in Chapter 4.

The final chapter provides a summary of the study and considers the contribution to knowledge as well as its limitations. Key recommendations for further research and are also provided.

1.11 Conclusion

This chapter has briefly outlined the focus of this study, its aims, objectives and research questions. The chapter also provided a detailed discussion of the research background and the methodology used. The next chapter provides an overview of the substantive policy context in Ireland.

Chapter 2

Women, pregnancy and loss in Ireland and beyond

2.1 Introduction

This chapter offers a discussion of the State's response to women's bodies, specifically pregnant bodies. The chapter then examines institutional responses to pregnancy and loss within the context of obstetric settings, presenting a broad summary of small body of Irish scholarship to date on women's experiences of pregnancy loss. It also considers the ways in which national scandals relating to pregnancy and loss have repositioned policy and medical practice over the last 40 years.

2.2 The State's response to women's pregnant bodies

In considering Traveller women's experiences of pregnancy loss in Ireland, it is important to locate this within in the historical context of the State's conceptualisation and response to women's bodies, specifically pregnant bodies.

According to (McCoole, 2004) in the years immediately after Ireland gained independence, the achievements[41] of the Irish women's movement, specifically those of the suffragettes, were systematically stripped and with it, women became "symbols, functions and instruments of the nation, guarantors of its 'legitimacy,' reproducers of its destiny (Smyth, 1995: 193). Irish women had played a prominent role in the struggle for independence and expected to be recognised as equals in the burgeoning new State. However, these efforts failed to be recognised in legislation or public life following independence. Instead, women became symbolic representations of Irish purity and virtue – a representation developed within the re-nationalisation project to purposely stand in stark contrast to that of British colonisers. Women's place later became enshrined in legislation as within the (marital) home and by extension out of the public sphere. Thus, the ideal identity of the Irish woman became constructed as virgin or mother. As Smyth (1995) reflects, women's maternal bodies became the sites for mobilising nation-building efforts, simply as "national property, common currency, boundary between *us* and *them*, there for the taking and the invading and the

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[41] This include milestones achieved by the Irish Women Workers' Union, the Irish Women's Franchise League, women members of the Citizen Army, Cumann na mBan, Inighinidhe na hÉireann and the election Constance Markievicz, the first woman cabinet minister in Western Europe

expending" (193). Defined by her reproductive role both literally and symbolically (Anthias and Yuval-Davis, 1989, 1995) womanhood and motherhood became represented as 'synonymous realities' (Smyth, 1992a: 143; Meaney, 1993; Valiulis, 1995; Gray and Ryan, 1997; O'Connor, 1998; Inglis, 2003) as Ireland embarked on a re-nationalization project which sought to legitimise a sense of shared national identity (Tuohy and Ó hAodha, 2009). 'Irishness' was hinged on a presumption of a homogenous Gaelic-Catholic Ireland, that was neither differentiated by ethnicity or gender. Traveller women remained invisible, effectively obscuring the material realities of women in Ireland and as a result, erasing gendered and ethnic diversity.

The Catholic Church was fundamental in the development of this new Irish State, as it exerted both ideological influences over social and sexual reproduction and institutional influences in terms of nation building (Fanning, 2004: 12). This is clearly evidenced with the heavy influence of male clergy within the Catholic Church[42] on the development of a new Irish Constitution in 1937. Specifically, in ensuring that the Catholic Church was recognised as the guardian of the State vis-à-vis the Fifth Amendment[43] (Article 44.1.3) which recognised the "special position of the Holy Catholic Apostolic and Roman Church as the guardian of the Faith professed by the great majority of the citizens" (Government of Ireland, 1972: Article 44.1.3). The considerable influence of this Church also meant that Irish law and State institutions became underpinned by Catholic social teaching, with patriarchal familism[44] becoming enshrined within the Constitution as a "moral institution, possessing inalienable and imprescriptible rights" (Murphy Lawless, 1993: 54). This status of the family became codified within the Constitution and with it, the relegation of women's economic, social and political roles to the limited parameters of the home. As a consequence, women's citizenship rested solely on her 'natural' and primary function as a wife and mother, which included her duty to bear children, within the context of a heterosexual marriage (Beaumont, 1997). Article 41 of the 1937 Constitution explicitly set out this criterion, with the State recognising the family as the:

> Natural primary and fundamental unit group of society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law [*in doing so]* The State, therefore, guarantees to protect the Family in its constitution and authority, as the necessary basis of social order and as indispensable to the welfare of the Nation and the State […] the State recognises that by her life within the home, woman gives to the State a support without which the common good cannot be achieved […] the State shall, therefore, endeavour to ensure that mothers

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[42] Members of the Jesuit Order in Dublin and Father John Charles McQuaid were key to advisors to Taoiseach Eamon de Valera in the drafting of the 1937 Constitution (Whyte, 1971; Beaumont, 1997)

[43] This Amendment was later removed in 1979 following a constitutional referendum

[44] Fahey (1998) describes patriarchal familism as a system based on distinct and hierarchical roles for women and men; with men holding the most authority as head of the family and women and children assuming second place to those of men.

> shall not be obliged by economic necessity to engage in labour to the neglect of their duties in the home. [Government of Ireland, 1937: 162-164]

It was in this context that women were endowed with a "particularly *favoured status*, which she was expected to live out within the home" (Kennedy, 2002: 5). Interestingly, while woman and mother are used interchangeably in Article 41, 'father' and the role of men remains glaringly absent. The prominence given to the nuclear family, and by extension women's role in supporting the family in this regard, reinforced both the State's and Catholic Church's familist pro-natalist ideology. This was also operationalised in the strict prohibitions on birth control[45] and abortion, which Kennedy (2004) argues is quite ironic given the State's obstructive policies to mothering.

According to Conroy (2004) the Church had "impregnated social relations with beliefs" (146) in relation to what was considered morally good and bad. This was coupled with prescribed scripts of how women would behave both sexually and socially, with sex only occurring within the confines of a heterosexual marriage and for the purpose of bearing children. However, as Guilbride (2004) reflects, "while economic factors prevented women from marrying and social values prevented them from becoming mothers […] they did not prevent them from becoming pregnant" [2004: 207]. These pregnancies starkly differed from those in which the Constitution and the Church prescribed as they demonstrated subversion and indeed disruption to Irish moral and social order, that is, by defying purity and chastity (Inglis, 2005). Considered 'illegitimate,' 'deviant' and 'shameful,' these pregnancies were not considered "necessary" nor "indispensable to the welfare of the nation and the State." They were also conceptualised as posing a higher risk for pregnancy loss, specifically in relation to infanticide and early/late neonatal death.

The *Report of the Commission on the Relief of the Sick and Destitute Poor, including the Insane Poor* proposed that, 'the illegitimate child, being the proof of the mother's shame is, in most cases, sought to be hidden at all costs" (Saorstát Eireann, 1927: 69). Consequently, a solution was developed to both hide and effectively punish women in mental asylums, Magdalene Laundries, Mother-Baby Homes and State prisons (Mahon et al., 1998; Hyde, 2000; Inglis,

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[45] In 1935, the Criminal Law (Amendment) Act introduced a prohibition on contraception by making them inaccessible, banning the sale, importation and by extension, the availability of birth control devices. Section 17 of the Act made it unlawful for individuals to "sell, or expose, offer, advertise, or keep for sale or to import or attempt to import into Saorstát Eireann (Free State) for sale, any contraceptive" (Government of Ireland, 1935: S17). Contraceptives were defined as any "appliance, instrument, drug, preparation or thing, designed, prepared, or intended to prevent pregnancy resulting from sexual intercourse between human beings" (Government of Ireland, 1935: S17,4). This was in line with the doctrine of the Catholic Church.

2005; Conlon, 2006, 2010; Millar et al., 2012; Fischer, 2016; Bradley, 2013, 2018). Women who are were convicted of infanticide[46] were also sentenced to periods of detention in these institutions, specifically Magdalene Laundries and State prisons (Mahon et al., 1998; Guilbride, 2004; Conlon, 2006, 2010;). Women and girls were incarcerated in these institutions following requests from family members, priests or other institutions e.g. courts, probation services, industrial and reformatory schools, health authorities and social services (McCashin, 2004: 173; DJE, 2013; Bradley, 2018). Operated primarily by the Catholic Church, these designated institutions for 'fallen' women and girls sought to conceal and confine pregnant bodies which were constant and flagrant reminders of female subversion to the nation's proscribed sexual morality. Luddy (2011) notes that these institutions afforded women and girls, and more importantly their families, a space to hide their shame, with the promise of returning to a 'normal' life after the birth (119). She furthers this by arguing that the institutions functioned to protect social norms, and although men were equally responsible for 'subverting' these norms, they were not subject to sanctions.

With an estimated 30,000[47] women and girls admitted to these institutions spanning 150 years, their bodies were subject to unlawful imprisonment, forced labour, systematic torture, neglect, physical, psychological and sexual abuse (CICA, 2009; JFM, 2012; DJE, 2013; DCYA, 2016; JFM Research, 2017). Their children, those who weren't adopted or fostered and remained in the homes or moved to industrial schools were subject to similar treatment. Some of these children were also subject to experimental vaccine trials[48] (CICA, 2009). This mass incarceration was supported by the State through direct financial transfers from "capitation" grants to Magdalene Laundries and indirect financial support in terms of cleaning contracts for the Irish Government. It also supported the re-internment of escaping women and girls by Gardaí and consistently failure to ensure that religious orders complied with State legislation relating to pay, pensions and other statutory obligations to employees, even when laundries

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[46] Guilbride (2004) provides a comprehensive overview of the legal cases involving infanticide in Ireland from the 1920s until the 1950s, which she argues grossly underestimated the actual incidence of infanticide in Ireland at that time. Guilbride (2004) describes how Infanticide Act recategorised the crime as "one equivalent to manslaughter, on the grounds that the balance of a woman's mind could be disturbed by the effect of giving birth, or, indeed, by lactation" (209). This, she argues, was motivated by politicans who were determined to classify mothers as 'mentally ill, deranged by virtue of their biology.' As a consequence, women and girls were sentenced to mental hospitals rather than laundries or prison. The sentencing for this crime also changed confinement to prison or the Magdalene Laundries was understood as temporary measures while incarceration in a mental hospital was often permanent.

[47] To date the actual number of women and girls interned in such institutions is unknown. In the State's report, *Magdalen Commission Report*, they estimate that approximately 10,000 women entered a Magdalen Laundry from the foundation of the State in 1922 until the closure of the last Laundry in 1996. Of the cases in which 'routes of entry are known,' 26.5% were referrals made or facilitated by the State (DJE, 2013: I).

[48] According historian Michael Dwyer, 2,051 children from Sacred Heart of Jesus and Mary facilities at Bessborough and Sean Ross Abbey in Roscrea, Tipperary were subject to these vaccine trials.

were routinely inspected under the relevant Factories Acts by departments and agencies (JFM, 2012).

In addition to Magdalene Laundries, unmarried pregnant women and girls were sent to Mother and Baby Homes (also referred to as 'maternity homes'). These homes were proxy based obstetric settings outside of maternity units and were registered, regulated and inspected by the State under the Registration of Maternity Homes Act 1934[49] (DYCA, 2016). Women were usually removed from the home shortly after childbirth and either returned to the Magdalene Laundries or other 'domestic situations' (Luddy, 2011). Babies stayed in the homes until they could be adopted, fostered, or until they were old enough to be sent to industrial schools. The conditions in the homes were extremely poor and overcrowded with inspectors reporting that the majority of infants were "emaciated and not thriving" (DCYA, 2014). Similar to the Laundries, women and girls were subjected to abuse and inhumane treatment. June Goulding (2012), a midwife contracted by a Mother and Baby Home to provide perinatal services reveals the extent of this mistreatment. Describing the home as a 'penitentiary' she writes:

> It was a place of imprisonment and cruelty […] where they were denied any contact with the outside world, denied basic medical treatment and abused for their 'sins.' [Goulding, 2012: 3]

Goulding goes on to describe specific manifestations of abuse such as scolding, humiliation and denial of medical treatment by nuns who ran the home. This included denying access to pain relief during labour, refusing to provide stitches after birth and denying antibiotics following the development of abscesses from breastfeeding (Goulding, 2012: 17). These homes were also sites where women experienced pregnancy loss;[50] with the Tuam home reflecting high levels of perinatal and infant death.[51] Local historian Catherine Corless estimates[52] that 796 infant deaths occurred in this specific home from 1925 to 1961 (McAuliffe, 2017) with the youngest just 10 minutes old and the oldest nine years old. Their remains were scattered under the former institution with some located in structures designed to contain sewage. In another home in Cork, 472 infant deaths and eight women's deaths[53] were recorded between 1934 and

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[49] Under this Act, 'maternity homes' were defined as "premises which are, either wholly or partly, used or intended to be used for the reception of pregnant women or of women immediately after child-birth. Exemptions from registration could be granted by the Minister "to any hospital or institution which is a maternity home but is not carried on for private profit." Section 10 of the Act required that homes registered under the Act shall keep records of: (*a*) every reception into such home; (*b*) every discharge from such home; (*c*) every confinement therein; (*d*) every miscarriage therein; (*e*) every birth therein; (*f*) every death therein; (*g*) every removal of a child therefrom and of the name of the person by whom and the address to which such child is removed; and within twelve hours after every such reception, discharge, confinement, miscarriage, birth, death or removal to enter in the said records the prescribed particulars thereof." (Government of Ireland, 1934: para 1)

[50] Currently, incidences of miscarriage in these institutions are unknown; it is anticipated that the Commission of Investigation into Mother and Baby Homes and Certain Related Matters will report on this rate records are examined in detail.

[51] 34% of children died in 1943; 25% died in 1944; 23% died in 1945; and 27% died in 1946 (DYCA, 2016).

[52] Corless' estimate is based on publicly available death certificates of 796 children who died at the home.

[53] This conflicts with the Annual Report of the Department of Local Government and Public Health, 1935-36 as noted in the *Report of the Inter-Departmental Group on Mother and Baby Homes* (DYCA, 2014).

1953. The infant mortality rates (IMRs) in these homes were consistently high at five times the national rate, with some homes reporting up to eight and 10 times the national rate. The causes of death include but are not limited to, 'debility from birth, respiratory disease, measles and influenza' (DYCA, 2016).

The precise number of women sent to these homes is unknown[54] and maternal and infant deaths in these settings is unknown in the absence of systematic data collection and a comprehensive State report[55] which was due in 2018, but has received a number of extensions and is anticipated to be published in 2019. Furthermore, it is unclear how many Traveller women and girls were sent to these institutions, given the lack of data collection and/or identification on the basis of ethnicity. However, there are references made in some Health Board inspection reports which referred to the children of 'itinerants.' One specific case involving a Traveller woman, Angelina Collins has been highlighted by number of news outlets and was included in Steven O'Riordan's (2009) documentary, *The Forgotten Maggies*. This was following Collin's family's campaign to remove her body from a mass grave burial site in a former Magdalene Laundry (Fogarty, 2017). Despite repeated requests to the Department of Justice and Equality and the Dioceses, the family have been denied permission to do so. According to Collin's daughter, Angelina was an unmarried Traveller woman who was, "snatched […] off my street and they put her in a Magdalene Laundry. And why? Because she lived and travelled the roads of Ireland in a caravan" (cited in Ward, 2015: para 14). Angelina's daughters were subsequently placed in an industrial school while she was sent to a Magdalene Laundry where she lived for another twenty-seven years before her death. In an interview, Collins argues that her mother was treated differently on the basis of her ethnicity and that her case was not unique, as the names on the death register for the Tuam site identified surnames, including common Traveller surnames:[56]

> There are many, many Traveller community names that appear on that list of 796 babies and children. My mum was treated differently because of who she was. I hate to imagine how many more Traveller children are in unmarked graves in Ireland. It just makes me so angry. [Ward, 2015: para 17]

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[54] The Commission of Investigation into Mother and Baby Homes and Certain Related Matters was established by Government in 2015 to provide a full account of what occurred in these institutions during the period 1922 to 1998. A sample of 14 institutions and a four County Homes have been identified by the Commission for investigation and includes reviewing the records of 70,000 mothers and a larger number of infants sent to such institutions.

[55] In 2015 the Commission of Investigation into Mother and Baby Homes and Certain Related Matters committed to publishing three comprehensive reports in this regard within a three years' period, it has experienced significant delays and has extended its deadline to 17 February 2019.

[56] In its report, the Commission on Itinerancy (Government of Ireland, 1963) presented a list of common Traveller surnames through its census in 1960.

Given that *Report of the Commission on Itinerancy* indicates that the highest number of Travellers resided in Galway in the period 1944–1961, it is possible that more Traveller women and girls were interned in these institutions. Collins statement challenges the homogeneous narrative of the women and girls in this context, and in doing so points to the intersectional identities and experiences of abuse and mistreatment on micro, meso and macro levels. With the exception of McDonagh (2016), stories of Travellers, in particular, women and girls have not been captured and/or included within the broader scholarship on institutionalisation in Ireland.[57]

The Tuam Mother and Baby Home was only one of numerous homes in Ireland, but an uncovering of a mass burial site in 2015 provided corporeal evidence to the nation and indeed to the world[58] of how the Catholic Church, and by extension the Irish State, dealt with pregnant bodies, more specifically, transgressive maternal bodies at that time. The last Magdalene Laundry closed in Ireland on 25 September 1996 (DJE, 2013) and numerous reports from JFM Research (2012, 2017) has reflected the levels of trauma, both physical and psychological that women continue to experience. In 2013, Taoiseach Enda Kenny issued an apology to the women and girls interned in Magdalene Laundries and acknowledged the State's role and collusion. In 2017, following the discovery of the Tuam site, he issued an apology on behalf of the State, describing the site as a social and 'cultural sepulchre,' he notes:

> We did not just hide away the dead bodies of tiny human beings, we dug deep and deeper still to bury our compassion, our mercy and our humanity itself. No nuns broke into our homes to kidnap our children. We gave them up to what we convinced ourselves was the nuns' care. We gave them up maybe to spare them the savagery of gossip, the wink and the elbow language of delight in which the holier than thous were particularly fluent. Indeed, for a while it seemed as if in Ireland our women had the amazing capacity to self-impregnate. For their trouble, we took their babies and gifted them, sold them, trafficked them, starved them, neglected them or denied them to the point of their disappearance from our hearts, our sight, our country and, in the case of Tuam and possibly other places, from life itself. We are all shocked now. If the fruit of her religious and social transgression could be discarded, what treatment was meted out to the transgressor herself? As a society, for many years we failed you […] We forgot you or, if we thought of you at all, we did so in untrue and offensive stereotypes. This is a national shame, for which I again say, I am deeply sorry and offer my full and heartfelt apologies. [Kenny, 2017: 1-6]

Kenny's apology reflects the first formal State apology to the women and girls who were interned in Magdalene Laundries. However, Kenny (2017) acknowledged the long-lasting

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[57] There is a paucity of research on unmarried/single Traveller women's experiences of pregnancy and motherhood in this regard, with the exception of this study which includes unmarried Traveller women's experience of pregnancy loss, Bradley's (2013) research on single women's pregnancy and motherhood in Ireland 1990–2010 being the only study to date to explicitly include the experiences of Traveller women.

effects of those experiences for women and committed to setting up a process to “help and support the women in their remaining years” (6) including supporting access to medical cards, psychological and counselling services and other welfare needs.

2.3 State/social responses to pregnancy and loss within the context of obstetric settings

The discourse surrounding the Mother-Baby Homes, or more specifically, the Tuam scandal focused intensely on precisely what Enda Kenny refers to in his speech, ‘those tiny human remains’ which appeared to be flippantly scattered throughout the property. While the number of remains are not the only measure of the impact of such violent and dehumanising treatment at the hands of these institutions, they sent reverberating shocks across the nation, serving as a stark reminder of the State’s systematic mistreatment and abuse of women and girls. Further, although the context in which these deaths took place and the manner in which they were discarded was met with public shock and outrage, the disposal of infant remains in unmarked graves was, and continues to be a standard procedure for Irish maternity units. Glasnevin Cemetery in Dublin, for example, has approximately 60,000 infants’ bodies buried in a communal burial site also known as the Holy Angel’s Plot (Garattini, 2007). There are also similar plots existing throughout country, including ‘Oileán na Marbh’ (Isle of the Dead), an island off the west coast of Donegal which contains approximately 1,200 infant remains (Maguire, 2011). Historically, the sites were referred to as *cilliní*[59] or children’s burial grounds located away from the consecrated burial grounds, were understood as ‘resting places’ for unbaptised children, including miscarriages and stillbirths.[60] On occasion, unchurched women, i.e. those whom did not receive a blessing after the birth of a child (see e.g., Hilliard, 2004) and died during childbirth were also buried in these spaces.

An estimated 1,400 cilliní have been identified in Ireland (Crombie, 1990; Dennehy, 1997; Murphy, 2011; Dennehy, 2016; Donnelly and Murphy, 2018) “characterized by marginality and peripherality, by absence of recognition within the general landscape and by lack of individualization of the graves” (Garattini, 2007: 194). According to Garattini (2007), this marginality is not only reflected in spatial isolation but also in terms of the rituality. Historically, the lack of professionalisation of protocols surrounding infant death within

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[59] Murphy (2011: 410) notes that cilliní has been referred to by various terms in both Irish and English: *caldragh, calluragh, cealltrach, ceallúnach, ceallúrach, and lisín. cill burial grounds, killeens, kyle burial grounds, and childrens’ burial ground*s.

[60] Murphy (2011), Dennehy (2016) and Donnelly and Murphy (2018) argue that cillíní were not exclusively reserved unbaptized children, as a number of other individuals could were denied burial in consecrated ground by reason of having “died outside the grace of God.” This included “suicides, excommunicates, those who died a sudden or unexpected death, the cursed, people of unknown religion, strangers to the community, the mentally disabled, and, upon occasion, unchurched women and women who died in childbirth” (Dennehy, 2016: 213).

clinical settings meant that male family members, usually the father, assumed responsibility for the burial and if, “the child was illegitimate or if it was an early miscarriage, then it would be buried at night so that no one would know” (Sugrue, 1993: 40). Women in general, but more specifically, mothers were not permitted to attend[61] burials as this was believed to exacerbate their grief and therefore absence would help them ‘‘get on with their lives;’’ a euphemism really, to ‘try again’ (Cecil, 1996a, 1996b; Garattini, 2007; 195). These restrictions were indicative of Catholic Church ethos, however, they also symbolised the precarious nature and social value attached to pregnancy loss and to infantile personhood (Sugrue, 1993; Cecil, 1996a, 1996b; McCreight, 2004; Garattini, 2007). It is in this context that pregnancy losses were understood as shameful, something to be hidden, silenced and “never to be mentioned again” (Garattini, 2007: 203; Davidson, 2007). While there has been progress in the development of protocols surrounding infant death within clinical settings in Ireland, miscarriage continues to remain precarious[62] (Department of Health, 2014b). Historically, remains were disposed of alongside clinical waste or in hospital incinerators (Cecil, 1996a; McCreight, 2001; Davidson, 2007) and again, this is in part due to a lack of clear policy in relation to the disposal of foetal remains for miscarriages, until relatively recently.[63]

2.4 Women’s experiences of pregnancy loss Ireland

As previously noted in Section 1.3, there is a dearth of Irish social science scholarship on pregnancy loss. This gap has been identified by Mulvihill and Walsh (2014) who were unable to identify any published Irish studies of pregnancy loss, “beyond guidelines for working with families following the death of a baby and on EOL (end of life) care” (2293). The authors acknowledge the work of McCreight (2008) in Northern Ireland which found that while women reported a “positive caring attitude from professionals, limitations in a medical clinical approach were identified, with women’s emotions generally ignored” (2293). In their qualitative study of eight women’s experiences of care in a rural Irish hospital following pregnancy loss, Mulvihill and Walsh (2014) argue that pregnancy loss has a significant imprint on the lives of women years after the event(s). Their work suggests that hospital social workers

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[61] A general consensus in the literature suggests strict prohibitions women attending attend burials, however, there appear to be some exceptions as indicated by Murphy (2011) in the case of Robin Flower (1978).

[62] A miscarriage is defined in this context up to 24 weeks and is not registered with the Registrar of Births, Marriages and Deaths. Stillbirths occurring in Ireland since 1 January 1995 must be registered, if the baby weighs at least 500 grams or has a gestational age of at least 24 weeks (Citizen’s Information, 2016). According to the Department of Health (2014b) “where there are foetal remains, these remains are buried according to parental choice either in a family grave or in the hospital plot […] where parents have not made their own arrangements for burial or cremation, the disposition of tissue following pregnancy loss is dealt with according to clinical protocols and gestational age […] In general hospitals, products of conception where there are no identifiable foetal parts are generally handled and disposed of as surgical specimens” (8).

[63] In 2012, the HSE and Institute of Obstetricians and Gynaecologists issued clinical practice guidelines in relation to the appropriate disposal of foetal remains.

have a role to play in mediating the impact of pregnancy loss and minimising risks of disenfranchised grief by “developing tailored and appropriate responses—ones which are responsive to a spectrum of need” (Mulvihill and Walsh, 2014: 2293). This was recognised by sociologist Rosanne Cecil (1996a); in her work with older women who experienced miscarriage in Northern Ireland, she argues that institutional responses to pregnancy loss matched that of the social responses, in that it was understood as an insignificant event for which there was no “vehicle for the shared expression for these sorts of loss, bereavement and remembrance” (Cecil, 1996a: 186). O’Connell et al. (2016) adds to this and note that until the 1970s it was common for medical staff in Ireland to sedate a woman following a stillbirth; this was to ensure that she would not see her infant, therefore avoiding attachment and grief. Women were not permitted to take photographs of their infant or retain any other keepsakes (e.g. hospital bracelets, blankets, etc.).

2.5 Socio-historical practices and pregnancy loss

In some instances, burial sites were not disclosed and women were encouraged to have another baby as soon possible “as if the one who died had never existed” (346). Helleiner (2000[1961]) refers to Travellers’ experiences of infant death, which she describes as the most traumatic events for Traveller women and men. Similarly, in responding to an infant death, some family members would endeavour to protect parents and ensure that they were not reminded of the tragedy, by destroying all photos of the infant. However, for others, these photos were placed in a prominent location in the home. Further, in memorialising these deaths, burials and anniversaries were understood as akin to that of an adult. Helleiner (2000[1961]) also refers the experience of Traveller women’s experience of racism in negotiating with officials following infant death, describing the experience one woman who had travelled and resided in a number of different locations following the death of her child. Seeking a birth certificate for another child at a later date, she was unable to remember the exact location of the baptism as her “mind was gone that year” (214). The staff member became angry at her inability to remember and accused her of attempting to fraudulently ascertain official documents. Goulding (2012) also provides some insight to how Irish maternity units responded to stillbirths, reflecting on her experience as a midwife in the late 1950s, Goulding describes one particular case in which no foetal heartbeat was detected following a long and arduous labour. Goulding, a midwife, was denied permission from the nuns to consult with a doctor:

> I was deeply distressed because I thought the doctor should have been sent for. We moved the girl to the almost full mother’s ward […] She never saw her baby. His body was buried in a patch of

> ground that had one cement crucifix, about two feet high, over an unmarked grave […] I felt that if the girl had been taken out to St. Finbarr's Hospital and had a Caesarean section performed, she would have had a live baby. However, I had no clout in that place and Sister's rules had to be obeyed [108–109]

As discussed in this chapter, the Catholic Church has maintained a strong influence on sexual and reproductive health policy in Ireland. This influence extends to service provision by informing obstetric practice in the hospitals and institutions in which it has dedicated considerable resources (Murphy-Lawless, 1993, 1998; McCarthy et al., 2008; Berer, 2013; McCarthy, 2016). It is important to situate women's experiences of pregnancy loss within key social, cultural, economic, historical, political and legal developments in Ireland. If a woman's primary role in Irish society is fundamentally regarded as the production of children, then the loss of a pregnancy/baby indicates a clear failure of her capacity to fulfil this role. Transgressive maternities as reflected in the bodies of women sentenced to institutions in Ireland parallels that of the transgressive mothers who are unable to 'successfully' bear children (McWhorter, 2014). These 'moral failings' (Layne, 2003) under a paternalistic guise of 'protecting women,' resulted in concealment and has had reverberating consequences even decades later (Cecil, 1996a).

In the past 40 years, Ireland has experienced a considerable shift in terms of religious, cultural and social responses to pregnancy losses. As Garattini (2007) notes, since the 1970s, memorialisation practices have moved from private to public spaces as mass burial sites for infants have increasingly become replaced by individualised graves marked by personal objects. Where parents opt for a communal plot, cemeteries such as in Glasnevin, parents can engrave a collective headstone with name(s) of their infants; this is not exclusively for stillbirths or early neonatal death, but also includes miscarriages. Parent support groups have been instrumental in driving this shift as they sought to make this "private place of shame" into a "public space of solidarity" (Layne, 2003: 239) in the absence of social and medical support. Layne (2003) traces the formal establishment of these groups in the U.S. in the 1970s with other groups spreading globally, including Ireland. The Miscarriage Association, a Little Lifetime Foundation (formerly ISANDS) and later Féileacáin were established to support parents whom had experienced pregnancy loss.

Aside from providing individual support to families and creating a space for women, and later their partners, to share their experiences, these organisations set out to collectively represent parents' interests, including informing policy and practice. This, coupled with high-profile cases reflecting serious failings in obstetrical practice in this regard,[64] specifically the case of Savita Halappanavar, and has informed contemporary Irish clinical practice in relation pregnancy loss. This includes acknowledging the importance of miscarriage for women, supporting maternal/foetal relationships and the recognition of grief and bereavement. In terms of stillbirth and neonatal death, national standards commit to ensuring that parents are encouraged to spend time with their infants and to participate in memorial practices[65] (HSE, 2016a). However, it is not clear to what extent these standards are fully implemented in hospitals as research indicates inconsistent and varied experiences of women (O'Connell et al., 2016; Cullen et al., 2017; Meaney et al., 2017). National guidelines also recognise the need for psycho-social support during and after loss, as there is a higher risk of anxiety, self-harm, depression and post-traumatic stress (HSE, 2012, 2016a; Nelson et al., 2013; Gold and Johnson, 2014; Gravensteen et al., 2018; Mutiso et al., 2018). Consequently, bereavement supports and mental health services have become increasingly integrated in maternity settings in Ireland. In 2017, the *Specialist Perinatal Mental Health: Model of Care for Ireland* (HSE, 2017b) was launched in line with mental health actions included in Ireland's first *National Maternity Strategy* (Department of Health, 2016). The model of care sets out a pathway for the overall design and delivery of perinatal mental health services in Ireland. This includes six dedicated clinical hubs within hospital groups with specialist perinatal mental health service, employing full-time perinatal psychiatrists and designated mental health nurses. The model of care commits to providing additional support for women who have experienced traumatic birth or the loss of a baby (67). Implementation of this model has been slow, with only three perinatal psychiatrists in the country, only one of whom is full time, and all three located in the Dublin area (Boylan, 2018).

2.6 Women's contemporary experiences of pregnancy loss in obstetric settings

Despite these developments, a number of issues remain outstanding and have been identified by women in their engagement with maternity services; this includes facilities, aftercare and communication (AIMSI, 2009b; O'Connell et al., 2016; Ellis et al., 2016; Cullen et al., 2017; Meaney et al., 2017). For instance, in 2009 the Association for the Improvement of Maternity

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[64] For instance, the national miscarriage misdiagnosis scandal in 2011 and HIQA investigations in maternity units

[65] This includes taking photographs, keeping items such as hospital bracelets, blankets, etc. and active participation and decision-making in terms of the burial.

Services (AIMS) Ireland[66] conducted an online survey[67] asking women to detail their experiences of services during pregnancy loss, specifically miscarriage. Most respondents reported accessing services through their maternity unit where doctors and midwives were responsible for treatment. In terms of how women believed they were treated, almost one in four women reported they received poor or very poor treatment. Some women distinguished between health service providers; medical and midwifery care were both described alternately as compassionate and abrupt. For example, one participant described her experience as positive as she felt she was treated with compassion:

> The care I was offered was faultless. I could tell every nurse, midwife and doctor had been carefully trained in how to deal with my situation. Not one person said anything I found offensive or hurtful. I received brochures from the hospital itself and ISANDS. The support service provided afterwards was excellent. [AIMSI, 2009a: 36]

However, other women suggested that they were not always treated with respect and compassion by health services. For example, as one woman reflected, “[it was] horrific, [I was] treated appallingly, wouldn’t treat an animal in the same way” (AIMSI, 2009a: 3). Another woman reported being “told off by a midwife, while she was miscarrying, for taking home her file” (2009: 3). Several women described feeling “just like a number, as staff told them that miscarriage often happens, that miscarriage is a daily occurrence for them” (3). The lack of facilities in services further compounded some women’s negative experiences, particularly when they were admitted to maternity wards. According to one woman, “hearing other women’s babies’ heartbeats was, truly, truly heart-breaking and I will never forget it” (AIMSI, 2009a: 3).

In terms of follow-up services, women reported accessing a wide range of services including, private counselling, hospital counselling, family, friends and Internet-based peer groups. Women expressed the need for comprehensive after-care supports, including practical information support (e.g. written information). Further issues identified by respondents included the lack of information and acknowledgement of the psychological impact of their experience. It is within this context that AIMSI (2009a: 13) recommended:

- Information booklets available/given to women and their families at GP surgeries, public health clinics and maternity units.
- Private examining rooms and separate ward areas for women experiencing miscarriage, i.e. away from antenatal and postnatal women and their babies;

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[66] Association for the Improvement of Maternity Services (AIMSI) is a voluntary advocacy group seeking to improve women's experiences in the Irish maternity system.

[67] A total of 106 women completed this survey.

- Further training for health care professionals and staff in attending and supporting women suffering miscarriages;
- The publication of a standard procedure and guideline policy document on miscarriage which will outline all steps from initial care procedures through to aftercare and follow-up. This document should also be made available on hospital websites for the benefit of service users and health care professionals alike;
- Review of hospital policy for support partners; and
- Review of aftercare and support services available to women.

The AIMSI research was published within the context of a policy vacuum. It would take three years after the AIMSI publication and the emergence of intense public scrutiny following a 22% increase in maternal deaths[68] and a national misdiagnosis of miscarriage scandal to effectively shift policy. The latter took precedent in terms of public concern with considerable media coverage reporting that some women had been misdiagnosed as having miscarriages. In two of the reported cases, a diagnosis of miscarriage had been made in error, and medical or surgical intervention was recommended to women, but subsequently it was found that the pregnancy was viable and the women went on to continue their pregnancies. Over the following weeks, several other women raised similar concerns with their hospitals. The HSE responded to the initial reports of misdiagnosis in 2010, with maternity hospitals and Early Pregnancy Assessment Units (EPAUs) around the country setting up dedicated helplines, to provide information and support to women who had questions about their diagnosis of early pregnancy loss. In total, 409 women contacted the helplines resulting in the establishment of the National Miscarriage Misdiagnosis Review and following a review,[69] 24 cases were confirmed.

Former Health Minister, Mary Harney, although initially refusing to comment on the scandal, when asked about her response to the scandal, remained resolute in her assessment of maternity services, noting that Ireland was "one of the safest places in the world to give birth and there's no doubt about that" (Carroll, 2010). Harney was specifically referring to Ireland's low maternal mortality rate,[70] however, *Confidential Maternal Death Enquiry* reported a 22% increase in the number of maternal deaths in the period 2010–2012 and noted that women born

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[68] This data is derived from the second Maternal Death Enquiry (MDE) publication and refers to maternal deaths that have occurred within 42 days postpartum. The MDE which established in 2009 with the task of carrying out confidential enquiries into maternal deaths occurring in Ireland (MDE, 2018). According to the report, maternal mortality was proportionally higher amongst minority ethnic groups of women who were not born in Ireland. This report does not disaggregate by ethnicity and therefore it is unclear how many Traveller women are represented in this cohort. It is also unclear how ethnicity is established (e.g) booking appointment, proxy based information by health staff, etc.

[69] 136 callers were informed that their concerns were unfounded and did not require review within the hospital; 273 clinical files were reviewed by hospitals, and of these, 33 cases met the case definition for review and were referred to the clinical review team. Of these 33, one case was found to be a duplicate, bringing the overall total to 32. Of the 32 cases forwarded for consideration, eight cases were closed as they did not meet the terms of reference.

[70] For the period 2010–2012, the maternal mortality rate was 10.5 per 100,000 maternities (95% CI 6.2-14.9)

outside of Ireland were over-represented in reported deaths (O'Hare et al., 2015, 2017). Furthermore, maternity services also experienced a rising number of medical negligence cases involving serious injury and death to either or both women and babies. For example, between 2007 and 2015, the HSE paid €66 million euros in legal fees based on medical negligence cases in maternity services.

The National Miscarriage Misdiagnosis Review was published in 2011 and identified five areas requiring immediate attention (HSE, 2011):

1. Guidance
2. Facilities and equipment
3. Clinical management
4. Education, training and accreditation
5. Support for women

Similar to the AISMI report, the first recommendation from the review was the development, dissemination and implementation of national guidelines for the management of early pregnancy complications. According to the HSE, in early 2011, national guidelines were developed and implemented across all maternity sites (RCPI and HSE, 2010; HSE, 2011,). Additionally, a National Clinical Programme for Obstetrics and Gynaecology was established in 2010 as a joint initiative between HSE Clinical Strategy and Programmes Division and Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland. The programme's key focus is the development of clinical guidelines and reports, with its first publication on foot of the National Miscarriage Misdiagnosis Review; the Ultrasound Diagnosis of Early Pregnancy Miscarriage in 2010.

Both the Review and Guidelines highlighted a key issue that had existed within Irish maternity services, that is, the inconsistency in access to ultrasounds and delay in treatment. Since 2000, the Royal College of Obstetricians and Gynaecologists (RCOG) recommended that all pregnant women should be offered two ultrasounds for the accurate dating of a pregnancy as well as the diagnosis of foetal anomaly. This two-stage ultrasound approach was endorsed by the National Institute for Health and Clinical Excellence (NICE) in 2008. However, currently there is huge variation in the number and type of ultrasounds provided by Irish maternity units and recent high-profile cases have also highlighted the lack of diagnosis of fatal foetal anomalies over the last number of years, suggesting that availability to foetal anomaly ultrasound remains inconsistent. This is also in the absence of national guidelines on the provision of routine obstetric ultrasound in Ireland, again despite commitments in the most recent *National Maternity Strategy* (2016–2026) (Department of Health, 2016) to ensure women's equal access to "standardised ultrasound services, to accurately date the pregnancy (and) to assess the foetus for ultrasound diagnosable anomalies as part of a planned Prenatal Foetal Diagnostic Service," (84) this has not occurred (Hayes-Ryan et al., 2017).

This report, alongside its recommendations was envisaged as a key step in ensuring 'woman centred' care during pregnancy loss. However, the report was published at the height of Ireland's financial crisis, with maternity services already experiencing drastic cuts. According to Thomas et al. (2014), from 2009 to 2013, financing of the Health Service Executive (HSE) fell by 22%, which amounted to almost €3.3 billion less in public funding. Staffing of public services also declined by 12,200 whole-time equivalents or 10% of total staffing from its peak in 2007. Maternity services experienced a decrease in overall funding, with budgets cut by more than 20%, and further midwifery staff shortages, taking Ireland below internationally recommended ratios to maintain clinical safety (KPMG, 2009; Holohan, 2014, O'Regan, 2014; Murphy Lawless, 2015; 208). This was also in the broader context of; (1) a growing demand for maternity services;[71] (2) a mass exodus of staff due to emigration; (3) pay freezes and an embargo on recruitment; (4) an over-reliance on agency and locum staff; (5) and an overall shift of fee paying private patients moving to public clinics, placing a significant burden on an already strained service (Kennedy, 2002; 2012).

Therefore, it is unclear how implementation of these guidelines was prioritised during this period. Furthermore, this was also in the context of the death of Savita Halappanavar in 2012, following the hospital's refusal to conduct a termination, despite an inevitable miscarriage. The Health Information Quality Authority (HIQA) initiated an investigation into the death of Savita Halappanavar and its findings it noted, that while "patients and members of the public are entitled to expect health care services that are at the very least safe and free from harm" (23), the Halappanavar clearly demonstrated "a failure in the provision of the most basic elements of patient care" (HIQA, 2013: 22). The report stressed the urgent need for the development of national maternity strategy and for review of all maternity services to "ensure that the services purchased and provided on behalf of the State are safe and meet international best practice

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[71] According to the CSO (2011a), there were 74,033 children born in Ireland in 2011 with 37,898 males and 36,135 females, a decrease of 1,141 births or 1.5% on 2010. The 2011 total is almost 28% higher than 10 years previously (2001) when there were 57,854 live births.

standards" (24). In another report commissioned by the HSE strongly advised and recommended:

> The clinical professional community, health and social care regulators and the Oireachtas to consider the law including any necessary constitutional change and related administrative, legal and clinical guidelines in relation to the management of inevitable miscarriage. [Arulkumaran, 2013: 6]

Peter Boylan (2018), an expert witness at Halappanavar inquest and former Chair of the Institute of Obstetricians and Gynaecologists added to this by noting:

> Savita died from sepsis and septic shock. There is no question about that. There were deficiencies in her care. There is no question about that […] If she had had her termination when she had asked for it, the question of developing sepsis and so on would not have arisen, we would never have heard of her and she would be alive today […] The most egregious example is Savita Halappanavar. She died as a consequence of the eighth amendment [Boylan, 2018: 1]

Two years subsequent to the Halappanavar case, in 2014, another scandal emerged, following an RTÉ Prime Time programme, *Fatal Failures*. The programme pointed to serious medical negligence and systematic failures, resulting in five perinatal deaths in Portlaoise Hospital. Similar to the miscarriage misdiagnoses scandal, the HSE established a national helpline and subsequent cases were reported. An official inquiry was directed by the Minister for Health in 2014. This initial inquiry, conducted by the Chief Medical Officer, supported the allegations in the PrimeTime programme, stating that health services withheld key information from women who were treated "in a poor and, at times, appalling manner with limited respect, kindness, courtesy and consideration" (Holohan, 2014: 66). The report was also clear in identifying a number of failures in patient safety which led to poor outcomes, in this instance, neonatal deaths, which could have otherwise potentially been prevented. In terms of women's experiences, the report noted that younger women were not spoken directly to and instead this was negotiated through "their mothers" additionally, there was a "lack of cultural sensitivity" (36). This latter statement, although ambiguous, points to heterogeneity in either the cases or in service providers; it is not clear from either the inquiry or the RTE PrimeTime programme.

Following this initial report, the Health Information and Quality Authority (HIQA) was tasked with conducting an independent investigation into the experiences of women and their families in their engagement with Portlaoise Hospital. HIQA received information in relation to 83 women and their families who had serious concerns about aspects of their treatment either at Portlaoise Hospital or at another maternity facility. From this sample, 15 women and 45 health related stakeholders were interviewed, this included staff working in Portlaoise Hospital.[72] While the report included the following disclaimer, “such recollections are personal perspectives on their experiences and that the validation and or verification of each of those experiences are outside the scope of the investigation” (HIQA, 2015: 4), women’s stories corroborated those included in the PrimeTime show and the Chief Medical Officer’s report (Holohan, 2014).

The report acknowledged that interactions between parents and the hospital were reported as unsatisfactory, with a “complete disconnection between the response the patient expected to receive and what they experienced at individual, local and national health service levels […] on an individual and systemic level” (137). In its findings, the report identified various incidences of grossly inappropriate behaviour from staff, including: verbal abuse directed towards women, isolation and refusal of doctors to address women during clinical examinations, only speaking to midwives. The report included examples of women whose experiences reflected a lack of compassion, humanity, dignity and respect during care (62). In one case, a woman recounted that some staff made her feel like “a naughty child or that she was a troublemaker when she questioned her care and treatment” (62). Another woman reported that she was made to feel guilty for her pregnancy loss and consequently this made her fearful of conceiving again. The report pointed to the absence of “basic acts of humanity,” particularly following loss and when parents were presented with their infants. For example, one couple stated that their baby was brought to them in a “metal box on a wheelchair covered with a sheet and pushed by mortuary staff” (HIQA, 2015: 63). In another case, one woman described how her baby’s body was squeezed into a box that was too small:

> She did not remove or hold her baby for fear of being unable to return him to the box. One woman stated that she had been told that this arrangement was intended to prevent upsetting the other mothers. [HIQA, 2015: 63]

The report acknowledges that such actions further compounded an already traumatic experience for couples, noting, “the manner in which these parents received their babies was recounted by them as being grossly inappropriate and extremely traumatising” (64). Another couple described being traumatised when contacted years later by the hospital and asked how they would like their baby’s retained tissue to be disposed of. The couple was unaware that

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[72] According to HIQA (2015: 28) the 45 individuals included staff from the: (1) Portlaoise Hospital at local level; (2) wider hospitals management group at a regional level whose role included responsibility for aspects of governance and risk management at the hospital; (3) HSE at national level whose role related to aspects of the governance and quality and safety of services at Portlaoise Hospital; (4) State Claims Agency with responsibility for the Clinical Indemnity Scheme; and (4) Department of Health.

retention of the tissue had taken place as they had not provided consent. Some parents who had lost their babies reported being told that their case was isolated, that such events were "not regular occurrences" (63). However, following the airing of the RTÉ PrimeTime programme, parents realised this was not the case and described feeling betrayed upon discovering that other parents had had similar experiences. Parents reported significant delays from the HSE when seeking a response to their requests for further information regarding their cases, with some parents reporting that they "encountered defensiveness and felt that there had been a cover-up" (HIQA, 2015: 64). Further, while the report points to a number of failures on individual and systemic levels, it also included examples where women reported feeling support by a single member of staff who showed kindness (62):

> The parents who had experienced some kindness and compassion remarked at how supported they felt by this and how this approach had helped them get through a difficult time. Some examples of such kindness and compassion were given by patients who told the Investigation Team of staff who had stayed with them beyond their shift just to provide them with support when needed, or who made home visits to them outside of their working hours. Person-centred care such as this can make an enormous difference to those dealing with a traumatic experience. [HIQA, 2015: 64]

The report goes on to acknowledge that women understood these experiences as an exception rather than the norm, and that overall, parents reported that they had been shown a lack of "empathy, sensitivity and advocacy" (62). The report acknowledged that maternity services were working within a vacuum in the absence of a comprehensive policy framework and recommended[73] the development of a national maternity strategy, including national guidelines, as a matter of urgency to support the delivery of safe, high-quality services in Ireland.

2.7 A shift in policy and practice?

This report consolidated decades of previous reports documenting women's experiences of mistreatment and abuse in obstetrical settings, in addition to scholarly research in this area. Similar to the national miscarriage scandal, the Tuam scandal and the Halapanavar case, the Portlaoise Report galvanised public indignation and support for an overhaul in policy and clinical practice. This, in addition to international pressure from human rights organisations and monitoring bodies[74] pushed the State to publish its very first *National Maternity Strategy* (Department of Health, 2016). The recommendations for a national maternity strategy can be traced back to 2001 when the *National Health Strategy* (Department of Health, 1994)

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[73] Other recommendations included the implementation of quality assurance mechanisms, reporting and management of serious untoward incidents and national laboratory alert system (HIQA, 2015: 34).

[74] This includes concluding observations from CEDAW (2005, 2017); CAT (2013, 2017, 2018); CCPR (2017);

committed to producing a plan to provide responsive, high-quality maternity care (16). Further, as discussed in Section 2.9, a key recommendation from the HIQA report into the death of Savita Halappanavar was that the Department of Health and the HSE work together to develop and implement a 'National Maternity Services Strategy' (HIQA, 2013: 11). In February 2014, at the publication of the Chief Medical Officer's Report on Portlaoise Hospital (Holohan, 2014) the former Minister for Health stated that the national maternity strategy would be developed and published by the end of the year.

In preparation for the strategy, the Department of Health initiated a public consultation which comprised of written submissions and two focus groups.[75] Focus groups were organised by the National Women's Council of Ireland and included a diverse range of women and representatives from a number of organisations, including Traveller organisations such as Pavee Point. A summary report of the main findings identifies a number of cross-cutting issues for inclusion in the strategy, including the need for: (1) high level service planning; (2) high level service quality and safety; (3) management of labour; and (4) further development and resourcing of support services (Keilthy et al., 2015: 13-14). In addition to ensuring that services were safe, the report also identified the need for 'woman-centred care,' ensuring that maternity services were delivered in "a respectful manner and afford(ing) dignity to all women" (70). In terms of Traveller women, the report recommended that a new model of care must encompass the principle of equality and ensure equality of access and outcomes for "vulnerable or socially excluded women including those with disabilities, migrant women, and members of the Travelling community" (70). The report acknowledged that Traveller women's experiences of 'stigmatisation' (99) by service providers can have a negative impact on engagement with mainstream maternity services, and as a result, Traveller women reported relying on Traveller Primary Health Care Projects[76] for support during their pregnancies.

The report also provided considerable scope in terms of exploring the role of maternity services in supporting women during and after pregnancy loss. According to the report, over 15% (n=144) of respondents indicated that they accessed services following a loss. In total, over half (58%) of respondents indicated that they received care following a loss in a hospital setting only. Relatively few respondents (9.7%) received follow-up care/support in the community or

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[75] Focus groups were held in Dublin and Cork. According to Keilthy et al., (2015) the Department of Health received 1,324 written submissions. Pavee Point Traveller and Roma Centre was the only Traveller organisation listed in the report as a respondent organisation, it also contributed to one of the focus groups. It is not clear if other Traveller organisations submitted and/or participated in the focus groups.

[76] The report identifies projects as 'Traveller health advisors.'

at home. However, a considerable number of respondents (16%) indicated that they received little or no follow-up care after loss (Keilthy et al., 2015: 25). According to the report, respondents identified the lack of compassion and empathy by staff for women experiencing a loss. This was in addition to the lack of dedicated hospital space with adequate privacy for those who have experienced a loss. For example, according to one respondent:

> I attended [hospital] and was an inpatient prior to the loss of my son at 33 weeks. No private room was available prior to the loss and the room used post loss is wholly inadequate positioned beside the pre-delivery ward with no privacy and very noisy. No funding is available to provide counselling to those who suffer stillbirth (Service user) [Keilthy et al., 2015: 46]

The report identified key recommendations to inform improvements to Irish maternity services on care following a loss. Greater staff sensitivity and support was highlighted as the main priority for care following a loss, with a focus on “compassion, empathy and kindness” (62). More privacy and better hospital facilities for those who have experienced a loss was also suggested by a number of respondents (17.9%). While in terms of support, almost one in five (18%) respondents recommended greater access to counselling services and mental health services. These recommendations featured in the National Maternity Strategy which was launched in early 2016. The Strategy, setting out a framework for a “new and better maternity service,” (Department of Health, 2016: 4) seeks to work in partnership with women to “rebuild and restore confidence in our services” (4). Focusing on “women and their individual needs” (4), the Strategy commits to ensuring that:

> Women and babies have access to safe, high quality care in a setting that is most appropriate to their needs; women and families are placed at the centre of all services, and are treated with dignity, respect and compassion; parents are supported before, during and after pregnancy to allow them give their child the best possible start in life. [Department of Health, 2016: 13]

In realising this vision, the Strategy identifies the following four priority areas (4):

1. A Health and Well-being approach is adopted to ensure that babies get the best start in life. Mothers and families are supported and empowered to improve their own health and well-being;
2. Women have access to safe, high quality, nationally consistent, woman-centred maternity care;
3. Pregnancy and birth is recognised as a normal physiological process, and insofar as it is safe to do so, a woman’s choice is facilitated;
4. Maternity services are appropriately resourced, underpinned by strong and effective leadership, management and governance arrangements, and delivered by a skilled and competent workforce, in partnership with women

Alongside these priority areas and the development of a new model of maternity care,[77] a key dimension of the Strategy was the establishment of a National Women and Infants Health Programme in 2017. The Programme was tasked with implementing the Strategy through governance and management of clinical maternity networks within hospital groups; this includes ensuring the appropriate allocation and targeting of new resources.

The Strategy makes only one explicit reference to Traveller women in relation to the lower average age of Traveller mothers giving birth. It does not acknowledge the clear gap in Traveller perinatal outcomes when compared with the majority population. Further, it does not propose any targeted actions to reduce higher rates of perinatal mortality,[78] maternal death and morbidity of Traveller women and other women from minority ethnic groups. The only explicit references to ethnicity are in relation to language barriers and domestic violence.[79] The Strategy does however commit to providing additional supports to pregnant women "from vulnerable, disadvantaged groups or ethnic minorities, and will take account of the family's determinants of health, e.g. socio-economic circumstances" (65). It is not clear from the Strategy what specific supports will be provided to women and/or how this will be operationalised.

Subsequent to the publication of the Strategy, HIQA developed comprehensive national maternity standards[80] to provide clear guidance to maternity services on "what safe, high-quality maternity services should look like" (HIQA, 2016: 10). Similar to the consultation process for Strategy, HIQA carried out a public consultation including focus groups with a range of stakeholders. It also established a Standards Advisory Group, comprised of health care providers and groups representing service providers. Given Pavee Point's role as a national Traveller organisation, and work to date on Traveller health, HIQA made request to the organisation to nominate a representative to join the Standards Advisory Group. I was nominated by Pavee Point to represent the organisation based on my knowledge and expertise in this area. This process provided me with a unique opportunity to contribute to the Standards by ensuring that Traveller and Roma women were explicitly named within the Standards and

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[77] One model of care is proposed, with the following three care pathways: (1) supported care; (2) assisted care; (3) and specialised care.

[78] See Corcoran et al. (2015, 2016)

[79] The Strategy states that minority ethnic women are "particularly at risk" for domestic violence (Department of Health, 2016: 42). While the Strategy refers to the work of the Women's Health Council (2009), it does not acknowledge the lack of robust and reliable ethnic data to inform this analysis. This is in the broader context of Ireland's equality data deficit which been highlighted by various human rights organisations and monitoring bodies, including CEDAW (2005, 2017). For further discussion see Section 3.5.1.

[80] The National Standards were developed using the framework of the *National Standards for Safer Better Health care* (HIQA, 2012)

targeted actions were included to support equality of access, participation and outcomes within service provision.

The Standards were published in 2016 and as the documents notes, the *National Maternity Strategy* and the *National Standards*, when implemented, "represent necessary building blocks to providing a consistently safe, high-quality maternity service, which will in turn work towards restoring public confidence in the service" (10). The Standards are organised into eight integrated themes[81] with an emphasis on ensuring a woman-centred care which respects women's dignity, privacy and autonomy. The Standards acknowledge the need for a targeted approach to ensure that women have equality of access, participation and outcomes within maternity services, and in doing so suggests that:

> Service providers directly engage with women, particularly women from disadvantaged and minority groups and communities, for example members of the Traveller and Roma communities, through regular engagement with representative groups. [HIQA, 2016: 34]

A key dimension of this is the need for robust data disaggregated on the basis of ethnicity to support effective decision-making in planning, designing, managing and delivering equitable services (148). In terms of pregnancy loss, the Standards set out clear guidance on communication, access to supports and services and staff training in relation to the psychological issues associated with pregnancy loss and perinatal death.

In addition to the HIQA National Maternity Standards, and informed by the recommendations of the Portlaoise HIQA Report (HIQA, 2015; Department of Health, 2016;), a substantive area of focus of the National Maternity Strategy was the improvement of support services for women who experienced pregnancy loss, with the Strategy committing to the development of nationally consistent standards of bereavement care. It is in this context that the HSE published the very first *National Standards for Bereavement Care following Pregnancy Loss*[82] (HSE, 2016a). These Standards were developed by the Investigations, the Bereavement Care Sub-group which was established by the HSE in 2014.[83] The purpose of the Standards is to "enhance bereavement care services for parents who experience a pregnancy loss or perinatal death"

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[81] This includes, person-centred care and support, effective care and support, safe care and support, better health and well-being, leadership, governance and management workforce, use of resources and use of information

[82] These standards were developed in response to a recommendation in the HSE National Incident Management Team (HSE, 2013) report which recommended the review, development and availability of counselling services for women, partners and families who have suffered any incident or bereavement in childbirth at each maternity site.

[83] The Sub-group was comprised of a number of health professionals from a range of disciplines, including obstetrics, foetal medicine, paediatrics, perinatal psychology, ultrasonography, chaplaincy, medical social work, midwifery, neonatal nursing, palliative care and specialist bereavement care.

(HSE, 2016a: 6) by focusing on four integrated areas: (1) bereavement care; (2) the hospital; (3) the baby and parents; and (4) the staff. While the Standards document refers to a national forum and public consultation on pregnancy loss,[84] it is not clear if Travellers or Traveller organisations participated in this process. Travellers are not explicitly named in the document, despite experiencing the highest rates of pregnancy loss of any other group in Ireland (AITHS Team, 2010a, 2010b). Further, while the Standards commit to ensuring 'culturally appropriate care' in accordance with the "religious, secular, ethnic, social and cultural values of the parents" (HSE, 2016a: 5) it is not clear how this will be implemented, particularly in the absence of clear protocols and/or mandatory anti-racism and discrimination training. This could potentially lead to health service providers working within a vacuum without any clear guidance on how to effectively ensure that care is provided in accordance with the Standards.

Lastly, aside from the development of new policy and standards in this area, Ireland also experienced a constitutional and legislative shift in 2018, with voters overwhelmingly[85] voting to repeal the Eighth Amendment from the Constitution. The Eighth Amendment[86] (Article 40.3.3°) provided the legislative prohibition on termination of pregnancy in Ireland (Quilty et al., 2015). According to Article 40.3.3:°

> The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right. [Government of Ireland, 1983a]

The Article criminalised the termination of pregnancy on grounds other than a risk to the life of the woman and carried a penalty of imprisonment for up to 14 years for women and their doctors.[87] The rationale for the insertion of the Amendment to the Constitution was to uphold both women and foetal rights equally. However, both the lives of the woman and foetus are competing in this instance and are at odds in biomedical frameworks, with foetal interests becoming prioritised over the basic rights of pregnant women and girls. This has presented serious challenges to medical practitioners in this area as they have been tasked with

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[84] This includes distributing draft standards to statutory and voluntary stakeholders for public consultation; engaging with stakeholders remotely through a web based questionnaire and directly through focus groups and interviews.

[85] The majority of voters (66.4%) voted 'Yes' to delete the subsection 3 of Article 40.3 of the Constitution: "The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right" and to substitute that subsection with the following: "Provision may be made by law for the regulation of termination of pregnancy" (Referendum Commission, 2018: para 1)

[86] The Eighth Amendment was inserted into the Irish Constitution in 1983 following a national referendum, with 53.67% of the electorate voting in favour of Article 40.3.3°.

[87] This was later reinforced under section 22 of the Protection of Life During Pregnancy Act 2013, which criminalises abortion even in cases of rape, incest, fatal foetal abnormality and serious risks to the health of the woman.

interpreting the Constitution while "caring for sick women" (Boylan, 2018: 10). According to Boylan:

> Article 40.3.3° gives rise to significant difficulties for doctors practising in Ireland and has caused grave harm to women, including death. Medical personnel have no difficulties in obeying clear legislation and medical regulations, but we are not trained for the complexities of constitutional interpretation, nor should we reasonably be expected to be. [Boylan, 2018: 10]

The Eighth Amendment has broader implications for pregnancy, labour and childbirth in Ireland as it has informed medical practice and restricted the rights of women to refuse interventions during pregnancy. According to the HSE National Consent Policy (HSE, 2017b: 41):

> The consent of a pregnant woman is required for all health and social care interventions. However, because of the constitutional provisions on the right to life of the "unborn" [Article 40.3.3°], there is significant legal uncertainty regarding the extent of a pregnant woman's right to refuse treatment in circumstances in which the refusal would put the life of a viable foetus at serious risk. In such circumstances, legal advice should be sought as to whether an application to the High Court is necessary.

Examples of this are demonstrated in the routine practice of artificially rupturing women's membranes (ARM) to induce labour (also known as "breaking the waters") without consultation or consent as in the case of Ciara Hamilton vs. HSE (2012);[88] to the performance of coerced and/or forced caesarean sections on women, despite explicit refusal as in the case of HSE v Baby B[89] (HSE vs. Baby B, 2016c). Given that the Eighth amendment has been repealed, the HSE Consent Policy document, and with it, medical practice must be reviewed and updated to ensure compliance with impending legislation.

Boylan (2018) and others have argued that the Eighth Amendment has provided the context for a number of legal cases in Ireland.[90] It has also been subject of scrutiny from national international monitoring bodies such as the European Court of Human Rights and the United Nations. In 2014, the UN Committee on Civil and Political Rights criticised Ireland's 'highly

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[88] This refers to the case of Ciara Hamilton vs the HSE (2012) who alleged that a midwife broke her waters without consent. Hamilton contended that the procedure was "unnecessary, that it was carried out at the wrong place, that the midwife should have consulted a senior obstetrician before doing the procedure and that she was seriously in error and negligent in doing it at a time when the baby's head was in a position in the pelvis that permitted the cord to prolapse downwards when the waters were broken." (Ryan, 2014: para 3). The judge dismissed this case, ruling that the midwife was not negligent as "she was the person entitled and authorised and qualified to make the decision" (89). The judge dismissed Hamilton's claims that she was not provided with the opportunity to consent to the intervention, noting that "I am satisfied that the probability is that Midwife Kelliher obtained the plaintiff's consent and informed her about the ARM that she was going to perform" (16).

[89] The case refers to the an application brought by the HSE for an order to force a pregnant woman to have a caesarean section against her will, in order to vindicate the right to life of her unborn child, as per Article 40.3.3° of the Constitution. The judge ruled that the performance of "invasive surgery upon the woman, against her will, would be a gross violation of her right to bodily integrity, her right to self-determination, her right to privacy, and her right to dignity." The judge refused the application and concluded that to order the forced caesarean section of a woman against her will was "a step too far to order the forced caesarean section of a woman against her will" (HSE vs. Baby B, 2016c:20).

[90] This includes the X case; the C case; A, B and C; D v Ireland; the Miss D case; A, B, and C v Ireland; Miss Y; Mellet v Ireland; and Whelan v Ireland. See Smyth (1992a); Murphy-Lawless (1993); Mahon et al. (1998); Kennedy (2002); Conlon (2010, 2006); and Quilty et al. (2015) for a comprehensive overview.

restrictive' nature and its failure to provide women with access to abortion in circumstances in which pregnancy is a result of rape, when a woman is carrying a foetus with fatal abnormalities and to explicitly recognise the priority of women's health in pregnancy. The chairperson, former UN Special Rapporteur on Torture, Nigel Rodley, stated that Ireland's abortion legislation treated women who were raped as 'a vessel and nothing more" (RTE, 2014: para 4). The Committee reiterated its concerns regarding Ireland's abortion legislation and the "highly restrictive circumstances under which women can lawfully have an abortion in the State party owing to Article 40.3.3 of the Constitution and its strict interpretation by the State party" (CCPR, 2014: 3). It also raised concerns about the requirement of "excessive degree of scrutiny by medical professionals for pregnant and suicidal women leading to further mental distress" (3). The Committee urged Ireland to review the legislation, including Article 40.3.3° of the Constitution.

In November 2015, the Taoiseach, Enda Kenny, proposed that the question and issues related to abortion be considered by a Citizens Assembly on the Constitution. Recommendations from this Citizens' Assembly report[91] and recommendations from a Joint Committee on the Eighth Amendment of the Constitution (Houses of the Oireachtas, 2017b) The Joint Committee recommended the removal of Article 40.3.3° from the Constitution without the introduction of any replacement or amendment text. It further recommended that:

1. termination of pregnancy should be lawful where the life or health of the woman is at risk and that a distinction should not be drawn between the physical and mental health of the woman;
2. provision for gestational limits for termination of pregnancy should be guided by the best available medical evidence and be provided for in legislation, and;
3. any assessments in relation to the termination of pregnancy where the life or the health of the woman is at risk should be made by no fewer than two specialist physicians and the law should be amended to provide accordingly.

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[91] In November 2015, the Taoiseach, Enda Kenny, proposed that the question and issues related to abortion be considered by "a Citizens' Convention on the Constitution, or whatever title would be appropriate" (Houses of the Oireachtas, 2017b: 36). The Citizens' Assembly was established in 2017 and after hearing from a number of experts and considering Article 40.3.3°, vote by a majority that Article 40.3.3° "should be replaced with a constitutional provision that explicitly authorises the Oireachtas to legislate to address termination of pregnancy, any rights of the unborn, and any rights of the pregnant woman" (36). The Assembly made further recommendations about what should be included in this legislation. This included the particular reasons for which termination of pregnancy should be lawful in Ireland, which recommendations included "risk to the health of the woman, fatal foetal abnormality, significant foetal abnormality, pregnancy as a result of rape and socio-economic reasons" (36). The Assembly recommended that a distinction "should not be drawn between the physical and mental health of the woman, and that termination of pregnancy should be lawful without restriction up to 12 weeks" (36). Recommendations were also made as to gestational limits in which an abortion could take place. On 29 June 2017, the Assembly's official report was published and submitted to the Oireachtas.

According to Chairperson of the Committee, Senator Catherine Noone:

> We need some change and in order to effect that we need to amend the Constitution to remove article 40.3.3°. After many years of public and political debate on the issue, the people will have their say. [Houses of the Oireachtas, 2017b:2]

This constitutional change paves the way for major overhauls in both health policy and reproductive/sexual health services. The result of the referendum has implications for the delivery of maternity services in Ireland, and in particular, the rights of women in obstetrical settings in relation to consent and to her overall care as service providers will have legal clarity on the 'risk' to life. According to the general scheme, which was published prior to the referendum, medical practitioners are permitted to carry out a termination of pregnancy, where they are of (1) reasonable opinion formed in good faith that there is an immediate risk to the life of, or of serious harm to the health of, the pregnant woman, and (2) it is immediately necessary to carry out the termination of pregnancy in order to avert that risk (Department of Health, 2018: 7). The Health (Regulation of Termination of Pregnancy) Bill 2018 provides the legislative framework for the provision of abortion care effective of 1 January 2019. A number of minor amendments to the proposed general scheme have been included such as clarification on informed consent. The Bill was formally presented to Dáil members in September 2018 and is currently under consideration by the government. Once this debate has concluded and amendments are accepted, it is expected that the Bill will be signed into law by President Michael D Higgins in December 2018. While this shift in legislation will provide a new context for maternity services and health practitioners, it remains to be seen whether or not this will radically shift social and institutional responses to women's bodies during pregnancy.

2.8 Conclusion

This chapter has traced the State's response to women's pregnant bodies in Ireland. First, it reviewed the institutional responses to both pregnancy and loss in the context of obstetric settings. This includes Magdalene Laundries and Mother and Baby Homes which the chapter argues were obstetrical settings by proxy. Next, it presented the small body of Irish social science scholarship on women's experiences of pregnancy loss and discusses the socio-historical practices related to pregnancy loss. Lastly, it provided an overview of policy development and medical practice in relation to pregnancy loss in Ireland. The next chapter focuses on Traveller related policy in Ireland, paying particular attention to the policies, practices and outcomes of institutional racism and discrimination as they relate to Traveller women.

Chapter 3

From assimilation towards inclusion: Traveller policy in Ireland

3.1 Introduction

In 2017, Ireland celebrated a historic moment, with the State formally acknowledging[92] Traveller ethnicity. In his statement in Dáil Éireann, former Taoiseach Enda Kenny, asserted:

> Our Traveller Community is an integral part of our society for over a millennium, with their own distinct identity – a people within our people (…) As Taoiseach I wish to now formally recognise Travellers as a distinct ethnic group within the Irish nation. It is a historic day for our Travellers and a proud day for Ireland. [Kenny, 2017: 1]

This formal acknowledgement was a direct result of a 32-year campaign led by Pavee Point, alongside other Traveller organisations who lobbied locally, nationally and internationally for State recognition. This was supported by numerous UN treaty monitoring bodies, European institutions, Irish equality and human rights bodies and two cross-party Oireachtas Committees. The campaign for State acknowledgement began in 1985 with Pavee Point, who rooted their analysis of Travellers rights as a minority ethnic group in Irish society, with discrimination and racism as key obstacles to be addressed at all levels. Traveller women's rights were placed at the crux of this analysis. According to O'Connell (1996, 1997) and Fay (2015), "if you recognise ethnicity, you recognise that Travellers experience racism. If you recognise that, then it means that you make efforts to address it" (para 1).

For Kenny, State acknowledgement of Traveller ethnicity was largely understood as symbolic, and not as an impetus for the creation of, "new individual, constitutional or financial rights" (Kenny, 2017: 1). However, for Travellers and Traveller organisations, ethnic acknowledgement, although not conferring any new constitutional rights or immediate benefits, demonstrated a paradigm shift in the State's conceptualisation and official discourse in relation to Travellers. In his announcement, Kenny affirmed Travellers' unique cultural identity as something that should be celebrated, promoted and respected, attempting to shift, although not dismantle, historical State policies that devalued Traveller culture. For Collins (2016), ethnic acknowledgement was not simply, "some abstract, ideological debate. The

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[92] This has been contemporarily framed in terms of' State recognition,' however, according to Fay (2018) Traveller ethnicity was always *recognised* by Travellers and Traveller organisations and therefore the issue was the "State acknowledging that reality"

recognition of Traveller ethnicity is fundamentally a human rights issue" (2). Further, he argues that, "in the absence of this unequivocal recognition, the subtext is that we are a dysfunctional, primitive community who need to be civilised and rehabilitated" (Collins, 2013: para 17).

For Collins (2013) and other Travellers (Quilligan, 2013; McDonagh, 2017), ethnic acknowledgement provided the basis for new relationships of respect, inclusion and solidarity between Traveller and non-Traveller communities. It would also create the conditions whereby Traveller language, culture and history are validated by the State, with the potential to impact on Travellers' collective self-esteem, confidence and status in Ireland (Collins, 2016). With symbolic and practical implications, the announcement provided an essential starting point in creating the conditions where Traveller needs are taken into consideration in the development and delivery of inclusive policies, programmes and accessible services, creating a roadmap:

> Within which the next steps can be taken towards full equality for Travellers as an ethnic group within the Irish nation. Rights gaps in the fields of accommodation, education, employment, health and other areas of Traveller life, however, have not disappeared overnight and remain to be addressed. [Crickley, 2017]

Travellers and Traveller organisations, while celebrating the monumental victory, reiterated Crickley's sentiments, recognising that a simple symbolic gesture by the State would not be the panacea for eliminating entrenched and structural inequalities experienced by Travellers. Nor would it, in and of itself, end anti-Traveller racism and discrimination in Ireland. As Pavee Point observed:

> Ethnicity, in and of itself, will not be a panacea for Traveller inclusion in Irish society however it is an essential part of the jigsaw for creating the conditions where Travellers can feel respected and their cultural identity is celebrated; and the State can no longer discount the lived experiences of anti-Traveller discrimination and racism. [Joint Committee on Justice and Equality, 2017: 16]

In Kenny's speech, he alluded to the fact that, Travellers were already explicitly named as a group protected from discrimination under Ireland's equality legislation since 1998.[93] Nevertheless, Travellers are one of the most marginalised and disadvantaged groups in Ireland, experiencing structural and systematic discrimination, State neglect and active prejudice (O'Connell, 1996, 1997). This has been observed both nationally and internationally by human rights organisations and monitoring bodies.[94] Months prior to State acknowledgement of

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[94] This includes observations from several UN treaty-monitoring bodies (CERD, CEDAW, CRC, UNHRC, CESCR), European institutions (ECRI, FCPNM, CoE), equality and human rights bodies within Ireland, including the Irish Human Rights and Equality Commission, the Joint Committee on Justice, Defence and Equality and UN Member State recommendations during the Universal Periodic Review (UPR) in 2011 and 2016.

Traveller ethnicity, in an urgent site visit to Ireland in late 2016[95], Nils Muižnieks, Council of Europe Commissioner for Human Rights, was, "deeply concerned at the persisting social exclusion and discrimination Travellers are confronted with in Ireland" and recommended that targeted policy measures and more effective involvement of Travellers is required to address the "serious inequalities that continue to affect the members of this [Traveller] community in accommodation, health, education and, in fact, all fields of life" (CoE, 2016: para 1).

As discussed in Chapter One, Traveller women's perinatal outcomes are exceptionally poor; with infant, neonatal and post-neonatal mortality rates reportedly the highest in Europe. This ratio is also higher when compared to other minority groups internationally (AITHS Team, 2010a). This research understands that experiences of pregnancy and loss cannot be decoupled from Traveller women's relationships to the people around them and their relationships to the broader historical, social, structural and cultural contexts within which they live (Mauthner and Doucet, 1998b: 126). This chapter focuses on those particular relationships, specifically Traveller women's relationship with the Irish State through its development of Traveller specific policy. Drawing on an intersectional analysis (Crenshaw, 1991; Cho et al., 2013), this chapter examines the policies, practices, and outcomes of institutional racism and discrimination as they relate to Travellers and Traveller women in Ireland. It argues that the racialization and problematizing of Travellers by the State as a "deviant sub-group within a homogenously imagined nation" (Fanning, 2009: 152) has resulted in operations, interactions and patterns of subordination, including racism and discrimination based on gender and ethnicity, all of which are embedded in Irish institutions, legislation and policy.

The chapter provides a broad background to the development of social policy in relation to Travellers in Ireland. It traces State policy as it affects Travellers, paying particular attention to the conceptualisation and consideration of Traveller women.

3.2 Historical overview: from assimilation towards inclusion?

While various works have considered the historical location of Irish Travellers in both British and Irish official historical documents (see e.g.,Helleiner, 2000, [1961]), Breatnach and Bhreatnach, 2006; Breathnach, 2006), the precise historical origins of Travellers is not entirely certain, given Travellers' oral tradition and nomadism. However, as Helleiner (2000[1961])

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points out, policy makers, scholars or 'cultural enthusiasts' generally fixate on *when* and *why* Travellers emerged as a distinct group rather than *where* they came from (Helleiner, 2000[1961]). This preoccupation with Traveller origins and 'emergence' in Irish society is very much reflected in the broader ideological and precarious position of the State in relation to Travellers, informing both State policy and practice. Discourses of Travellers origins and identity are taken up in the dominant discourse and practice, becoming reified and codified. Traveller origin theories in particular, have been used to perpetuate a powerful subtext in support of a hegemonic order; that is, that Travellers are "dysfunctional, primitive, a people who need to be rehabilitated and civilized" (Collins, 2016). This has been used to stigmatise Travellers and deny them a ethnic identity, validating an exclusionary social order and legitimising anti-Traveller racism and discrimination in Ireland.

3.2.1 Tracing Traveller 'origin' theories

Attracting scholarly attention since the late nineteenth century, Irish Travellers have been referred to by a variety of racialized (Miles, 1989; Anthias and Yuval-Davis, 2005) and offensive terms including, *gypsies, vagrants, tinkers* and *itinerants;* with *Traveller, Traveller/ing Community* emerging in policy and political discourse during the early 1980s (Helleiner 2000[1961]: 7; Breathnach, 2006). As Matache (2017) argues, the uncritical use of ethnonyms contributed to the construction of Traveller identity, institutionalising discourses of 'misfits' and 'deviants,' with such approaches constituting obstacles in a much longer struggle to amend narratives, assimilationist policies, and discrimination against Travellers.

Historically, academic interest in Travellers generally centred upon issues of ethnicity and cultural identity/difference (Gmelch, 1985; McCann et al., 1994; Helleiner, 1997; Breatnach, 2006; Breatnach and Breathnach, 2006), with early scholarship also developing Traveller 'origin' debates and theories, influencing Traveller identity markers. Traveller origins have been marked by three dominant theories, as:

1. descendants of misfits who were unable to function in 'settled' society;
2. descendants of families who were evicted during the plantations following the collapse of the old Gaelic society in the seventeenth century; and
3. an abjected population from the Famine in the mid-nineteenth century.

The latter origin narrative of Travellers as descendants of peasants dispossessed from their land and forced to adopt a nomadic lifestyle through times of famine and eviction during the

Cromwellian Settlements emerged in the 1950s and achieved dominance from the 1960s to the 1980s (Helleiner 2000[1961]). Breatnach (2006) and Helleiner (2000[1961]) argue that such a simple theory was convenient in appealing to popular nationalist understandings of Ireland's past, and justified explicit attempts of the state to 'settle' Travellers during the 1960s and 1970s through various settlement schemes (Helleiner, 2000[1961]). These initiatives were promoted as a national duty on the part of a benevolent and compassionate Irish State, which was simply correcting the wrongs of the past by 're-settling' victims of British colonial rule (Helleiner, 2000[1961]: 30). The power of this theory according to McDonagh (2000) is that:

> It allows people to believe that prior to this, Travellers would have been settled people. Hence, Travellers appearing in 1840 would mean that they were in some way 'failed settled people' and hence the whole concept of rehabilitation and re-assimilation comes into play. [McDonagh 2000: 22]

According to McDonagh, this account enables those in the majority population to perceive Irish Travellers as "failed settled people" or "essentially drop-outs from normal society, victims of their own inadequacy or of harsh colonialism, in addition to legitimizing claims that Travellers were "pathologically unfit for national society" (MacLaughlin, 1998: 417). This 'drop-out theory' is mere conventional wisdom, which was given academic legitimacy by being uncritically accepted and reiterated by U.S. anthropologists George and Sharon Gmelch in the late 1970s (Ní Shúinéar, 1994: 68). For Ní Shúinéar (1994), such postulations had, and continue to have, serious implications for settled attitudes and government policies towards Travellers, as clearly reflected in the contemporary works of MacGreil (2010). Watson et al., (2017) and McGinnity et al. (2017). Breatnach (2006) add to this by observing that some Travellers have internalised this narrative of dislocation of colonisation, serving to illustrate the effectiveness of such tales in an Ireland where the Anglo-Irish relationship has assumed "political and cultural centrality" (Breatnach 2006: 54). Kenny notes that this "mythic tradition is part of internalised discourse, feeding self-constructs that enable the sedentary to continue their prejudice, and the Traveller to accept it" (32). The power in such myths, she argues is that they have served their purpose in validating hegemony and in legitimising the notion that mere assimilation and absorption into the general community would solve Travellers' exclusion and marginality in Ireland.

However, the belief that Travellers emerged as a 'misfit community' is not simply confined to academic discussions, as Michael Hayes (2006a; 2006b) demonstrates in his analysis of the 1952 Tinkers Questionnaire. In this work, Hayes argues that the 'new' Irish essentialism that accompanied independence in 1921, was used as an ideological framework of 'control' or 'representation' which was quite similar to what had previously occurred in Ireland under British colonial rule. This teleological version of 'Irishness' was reductive by nature and, consequently, masked the existence of heterogeneity in Irish culture. This had particular consequences for minority groups, such as Travellers, who had always, to a certain extent, occupied a marginal position in mainstream Irish society (Hayes, 2006b: xi). Exploring the State's attempt to define itself following independence, Hayes (2006b) posits that the 1952 Tinker Questionnaire was simply one element of the emergent nation-State's attempt to re-nationalise and 're-Gaelicise' Ireland (Hayes, 2000b). In this text, Hayes highlights and analyses some key elements and most significantly, the discourse of respondents in pathologising Travellers as 'other.'

The Questionnaire which served as a basis for the Irish Folklore Commission (IFC) report in 1952, described Travellers as, "one of the oldest classes of Irish society." The IFC in acknowledging the, "dearth of knowledge among the settled community about Travellers," issued a questionnaire in the hope that, "a representative documentation on certain aspects of the tinkers life may be compiled, before it is too late to do so" (IFC, 1952: 5). More than 300 retired school teachers around the country were sampled for the questionnaire. This was ironic as Travellers were excluded from the sample, yet the knowledge contained in the responses were used as an authoritative reference point on Traveller culture. Respondents were asked to report on a small number of reductive and seemingly self-evident objective characteristics, namely sexuality, dirt, crime, fighting and so forth. Respondents were also asked to record their understanding of Traveller origins, specifically, how "it has happened that they took up the nomadic life?" The responses were varied, with some attributing Travellers' origins to a pre-Christian period (IFC, 31), while others assumed Travellers emerged as a result of exile, crisis, economic collapse, or "foreign perfidy" (Hayes, 2006a; Breatnach, 2007: 30). Hayes (2006b) argues that each origin theory considered Travellers as a deviant subculture, or 'other,' by portraying the settled tradition as 'normal' (127-42). The report and surveys became a standard, authoritative source on Travellers for the next 40 years, serving as a justification for anti-Traveller racism (Helleiner, 2000[1961]) as well as acting as a catalyst for assimilation policies (McDonagh, 1994; Helleiner, 2000[1961]; Hayes, 2006a:12).

The most recent origin analysis was provided by a genetic-based study, led by Royal College of Surgeons in Ireland (RCSI) and the University of Edinburgh (Gilbert et al., 2017).

Examining DNA samples of 50 Irish Travellers, 143 European Roma, 2232 non-Travellers (Irish), 2039 British and 6255 European or worldwide individuals, researchers estimate that Travellers separated from the majority population before the Great Famine, at least 12 generations ago. This translates into approximately 360 years, dating back to the mid-1600s. According to Mac Gréine (1931) historical records indicate that Travellers historical roots can be traced back to at least the 12th century, with the 'Acte for tynkers and pedlers,' passed in 1551. This was the first law prohibited nomadic trading 'in these islands,' aimed at curbing the activity of 'tynkeres,' a term that would later be used to described Irish Travellers. However, historian Eoin MacNeill argues that Travellers descended from Celtic and pre-Celtic industrial communities (MacNeill, 1937: 82), something which is supported by Travellers and Traveller organisations.

While Traveller origins remain largely contested, Ní Shúinéar (1994) argues that such questions surrounding historical origins are matters for historians and linguists, not policy makers. She notes that the tireless origin controversy surrounding Travellers has acted in many ways as a "smokescreen," or as political dilemmas masquerading as academic ones, which seek to prevent individuals from addressing the pragmatic question surrounding the current marginalised position of Travellers in Irish society (73). Further, she argues that debate is dominated by the unspoken assumption that the validity of Traveller ethnicity "is up for definition and approval by the majority population" (55). Helleiner (2000[1961]) adds to this by arguing that nationalist origin narratives appear to be "part of larger post-colonial nationalist discourses in which Irish citizenship, identity and culture are opposed to the colonial past" (Helleiner 2000[1961]: 50), diverting attention from the economic and political processes and relations of power that have produced and sustained Travellers' low status, marginalisation and disadvantage in Ireland.

3.3 Historical anachronism to the problem of itinerancy: Commission on Itinerancy

This study argues that the narratives surrounding Traveller origins are fundamental to any contemporary analysis in relation to Travellers in Ireland, as they have underpinned State responses and policies. The conceptualisation of Travellers as 'dropouts,' 'misfits' and a community of people that merely required intervention and rehabilitation through assimilation is clearly evident in State policy beginning with the first official Government Commission in 1960. The Commission was established to respond to the increasing visibility of Travellers in urban towns and cities following the introduction of a general programme of economic modernisation (MacLaughlin, 1995; Kenny, 1997). Prior to this, from 1940 to 1960, the only evidence of official State interest in Travellers was in the publication of the Garda Census, which was conducted for Department of Justice every five years. According to Kenny (1997) little can be said about the specific ideology of this practice, although it could be deduced that Travellers in this context were reduced to being counted only as objects of police attention.

During the 1960s, traditional Traveller trades such as tinsmithing trading became somewhat futile as mechanisation replaced the need for casual labour; motor vehicles reduced the need for draft animals on farms, making distant shops accessible and plastic replaced the need for tin utensils (Kenny, 1997; Fanning, 2009). Traditional skills were replaced by mass production of goods and services, displacing Travellers both socio-economically and spatially as they were forced to migrate to urban areas. According to MacLaughlin (1995) the move from rural Ireland to urban cities presented Travellers with more problems than opportunities as they were forced to compete for land with non-Travellers and the increase in modern technology, resulted in long-term urban unemployment and an increased dependency on the welfare State (MacLaughlin, 1995: 1).

Furthermore, Travellers experienced a high degree of structural discrimination as much of the landscape that they had formerly passed through and temporarily inhabited was now "literally reconstructed and rearranged by new infrastructural developments that clearly were mal-developments for travelling people" (MacLaughin, 1998: 434). Collins (2017a) asserts that this urban move has arguably influenced Traveller culture, lifestyle and health in fundamental ways. While modernisation introduced significant improvements in terms of health for the majority of the Irish population, it increased the social, political and economic impoverishment and isolation of Irish Travellers (Moore, 2012: 30–31; Collins, 2017a). Such a move ensured more contact and confrontation with the settled community, although as Gmelch (1985: 137–8) has observed, there was evidence to suggest that Travellers were already living in houses in urban cities during this time, albeit in concentrated familial groups and separate from other Irish people (Gmelch, 1985; Helleiner, 2000[1961]). While some Travellers managed to find new occupations and economic opportunities in urban cities, such as selling scrap, others were forced to beg (Kenny, 1997). Heightened visibility of Traveller camps around Dublin, Galway, and Cork also contributed to public tensions with Travellers, as they were perceived as a "nuisance, particularly to the tourist trade" (90). According to Harvey (2013) and Collins (2017a), the precarious situation of Travellers at that time, thrown into sharp relief by rapid economic change and urbanisation, provoked the establishment of ‘itinerant settlement committees,’ which sought to address the ‘itinerant problem.’

3.3.1 Commission on Itinerancy

The Commission on Itinerancy was established by the Government in 1960 under the auspices of the Department of Social Welfare. This is significant as it represented a paternalistic approach to Travellers, reaffirming a widely held perception of Travellers as destitute and ‘in need of charity, rather than rights’ (O’Connell, 1997: 3). The Commission was tasked with “promoting the absorption of Travellers into the general community” (Government of Ireland, 1963: 11) through an enquiry:

> Into the problem arising from the presence in the country of itinerants in considerable numbers; and [an examination of] the economic, educational, health and social problems inherent in their way of life [Government of Ireland, 1963: 11].

Comprised of non-Travellers, the Commission members were nominated on the basis of their “known interest in, and specialised knowledge of, some particular aspect of the itinerant problem,” (Government of Ireland, 1963: 111), the government considered itself, “fortunate” to have “such a well-balanced Commission” (Government of Ireland, 1963: 111). The language used in the Commission’s terms of reference was instructive as to the State’s ideological approach to Travellers as it was resolute in acknowledging that, “there can be no final solution of the problems created by itinerants until they are absorbed into the general community” (111).

The term ‘itinerant’ is reflective of popular origin narratives outlined in the previous sections. It provided a racialized and fixed construction of Traveller identity, casting Travellers as “deviants who failed to confirm to the way of life of the majority population” (O’Connell, 1996: 4). According to McDonagh (2017), ‘itinerant’ and ‘no fixed abode’ were documented on Traveller’s birth certificates, officially codifying the stigmatisation of Travellers, something which McDonagh remarks was “an attempt to make us feel inferior. A legacy of Irish racism” (para 6). The term itinerant defined as “persons with no fixed abode, [who] habitually wandered from place to place and lived in poverty” (O’Connell, 1996: 4). It is within this context that a number of recommendations were submitted and the formulation and implementation of a national settlement project with the avowed objective of assimilating Travellers into the settled community began (Helleiner 2000[1961]). The Commission provided a specific focus on gender, with Traveller women and girls specifically identified by the Commission as being the ‘greatest hope’ for State settlement:

> A number of itinerants, particularly, women and girls, have expressed to members of the Commission a desire for a better way of life, and it is the view of the Commission that the greatest hope for a movement to settle lies in the desire of the young married women and the girls to improve their lot. As the women are more in contact with the homes of the settled population they see what is enjoyed by others. [Government of Ireland, 1963: 87]

The Commission directly referenced the 'desire' of a number of Traveller women and girls to have a 'better way of life,' implying that extensive consultation with Travellers had occurred prior to the publication of the report. Yet this was not the case. The Commission was comprised of eleven non-Traveller members,[96] and with the exception of one woman, it was exclusively male. Members represented law enforcement, agriculture, churches, local government and health officials, and the Department of Education. Travellers were not represented in its ranks, nor were they formally consulted (Pavee Point, 2005a). According to the report, the Commission met with only one Traveller representative and consequently felt that the "formality of the occasion tended to make them [other Travellers] ill at ease and to leave most of the discussion to be conducted by their spokesman" (Government of Ireland, 1963: 30). Instead, the Commission would unexpectedly approach Traveller families, something that Pavee Point (2005a) argues, effectively privatised consultation making it impossible for collective issues to be raised and consequently addressed.

It is within this private context that the Commission reported that Traveller women and girls expressed discontent with their lives, which was in many ways inevitable given the lack of provision for Traveller specific accommodation and the growing anti-Traveller discourse amongst the settled population. Traveller women were generally the interface between both communities as they engaged with State services and agencies on behalf of their children and families. This also meant that there were more opportunities for direct discrimination as they were more easily identifiable and locally visible than Traveller men (McDonagh, 1994; Helleiner 2000[1961]; Pavee Point, 2011: 34)

The desire for 'a better way of life,' as reported by the Commission is underpinned by an assumption that Traveller women aspired to live similar to settled housewives with whom they came into contact while selling goods/and or begging (Helleiner, 1997; 2000[1961]: 166; 2003). This in many ways exposes the cultured, classed, and gendered nature of the report. At the same time, the Commission constructed Traveller life as harsh and 'primitive,' relying

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heavily on the position that male Travellers were no longer adequate enough to support their wives and households due to a decreased demand for traditional occupations such as tinsmithing (Government of Ireland 1963; Helleiner 2000[1961]). Aside from perpetuating the popular supposition that male work was the most substantial, this perspective also gave a limited view of the Traveller economy in addition to assuming a cynical tone about its survival (Helleiner, 1997: 279). Helleiner (1997) argues that such understandings of Traveller economy not only dismissed the critical contributions of Traveller women and children, but also portrayed women's activities lacking ‘skill’ and/or ‘pride’ (Government of Ireland, 1963: 91) when compared to the occupations of their male counterparts. Frequent references to "begging" for example by the Commissioners, obscured how interactions established by Traveller women with the non-Travellers combined both requests for assistance and the sale/bartering of a variety of goods and services (Helleiner, 1997: 279).

Instead of recognising the significant contribution of Traveller women and identifying further opportunities for women’s participation in the Traveller economy, the report proposed reorganising the Traveller economy so that it could follow a middle-class model of male breadwinners and female ‘homemakers.’ This is something that has extended beyond the Traveller community, as women in Ireland were already defined by their ‘special’ place in the home as per Article 41.2 of the Irish Constitution, in which the State:

> Recognises that by her life within the home, woman gives to the State a support without which the common good cannot be achieved. [Government of Ireland, 1937: 162]

This, according to Conlon (2010) has resulted in “an archetypal patriarchal discourse” with the role of mother both imagined and institutionalised. Further, incorporating a discussion of the need for adult education for Travellers, the Commissioners proposed that “tuition in housekeeping, cooking, washing, child hygiene, and other domestic knowledge might be made available for the women folk, if necessary, in their dwellings” (Government of Ireland, 1963: 70). Such emphasis on the domestication of Traveller women is quite apparent in the discussion of Traveller women who were married and whose mothering practices and “homemaking” were assured to become full-time occupations (Government of Ireland, 1963; Helleiner, 2000[1961]: 166). Such explicit distinctions drawn between males and females provide clear examples of the significance of gender in State development (Anthias and Yuval-Davis, 2005).

Moreover, while the report stressed the importance of solving the 'problem' of Travellers, it simultaneously supported aspects of Traveller culture, specifically, the gendered nature of Traveller families. The Commission praised the existence of male family heads who were "always held in respect by the other members" (Government of Ireland, 1963: 37), and who placed a "strict watch" on Traveller daughters and women. The Commissioners were also impressed in the modest dress and demeanour of Traveller girls, commending high standards of sexual morality and even expressing concern that Travellers might "be imperilled" through exposure to "the less desirable incidents of life in the settled community" (Government of Ireland, 1963: 90). Helleiner (2000[1961]) observes that remarks contrasted substantially with the assimilationist tone of the Report, revealing a gendered conservativism on the part of the Commissioners (Helleiner, 2000[1961]: 166). Interestingly, the publication of this report coincided with a historical shift in relation to women throughout Europe and the United States; with the emergence of the sexual revolution and second wave feminism. In Ireland, this also marked the formal legalisation of oral contraceptives (Department of Health, 1995; Bloom and Canning, 2003: 239).

While the report focused on the gendered roles and sexual morality of Travellers, Traveller women's perinatal health was a chief concern for the Commissioners. Noting the high rate of Traveller infant mortality, the report recommended frequent health visits to sites by personnel from the Public Health Department of the local authority. The key purpose of visits was to inform Travellers about the various available health services and to encourage childhood vaccinations. The report specifically recommended that Traveller women should receive perinatal care, including early prenatal care and postnatal care for both the mother and infant. The Commission reasoned that once Travellers received the aforementioned interventions and essentially became 'settled' in standard accommodation, infant mortality would decrease. This has unfortunately not been the case, with the current Traveller infant mortality rates 3.7 times the national rate (AITHS Team, 2010a).

3.4 Review body: assimilation to integration

In the subsequent two decades, the Report of the Commission provided a framework for promoting Travellers' assimilation into the general population; predicated on a rehabilitative model with State imposed technical interventions, which were 'for' rather than 'with' Travellers (O'Connell, 1997: 3). This approach came to be regarded as "assimilatory and no longer appropriate" (Harvey, 2013: 16); it became evident to the government that the

Commission on Itinerancy could not effectively 'solve' the 'itinerant problem' and a subsequent Committee, the Travelling People Review Body ('Review Body) was established in 1981 tasked with revaluating Traveller specific policy and recommended ways to improve the "existing situation" (Government of Ireland, 1983b: 1). Like the previous Commission, the Review Body had limited active Traveller participation; although Traveller representatives from the National Council for Travelling People were included, their input into the final report was limited.

Calling for a full review of the services for Travellers with a reappraisal of past programmes and policies to "assess their appropriateness" and to look towards fresh approaches, the Review Body was established under the auspices of the Departments of Health and Environment. This reflects a deviation from the previous Commission which was intensely focused on welfare. The new Body represented a primary concern with accommodation, education and health as associated with personal/family health and welfare. The key objective of the Body was to review, "current policies and services for the travelling people and to make recommendations to improve the current situation," it also sought to address the needs of Travellers, "who wish to continue a nomadic way of life." This signified a seismic shift from the previous assimilationist approach evidenced in 1963 to an integrationist approach in 1983. This is clearly reflected in the language used by the Review Body, with absorption, assimilation and rehabilitation wholly rejected and replaced with the term integration. The term 'itinerant' was also replaced with 'Traveller.' In critiquing the Commission on Itinerancy, the *Report of the Travelling People Review Body* noted:

> The Review Body considers that in the light of experience and current knowledge the concept of absorption is unacceptable, implying as it does the swallowing up of the minority traveller group by the dominant settled community, and the subsequent loss of traveller identity. It is suggested that it is better to think in terms of integration between the traveller and the settled community. It is a long and complex process implying adjustment of attitudes towards one another, both by the traveller and by his neighbours in the settled community. [Government of Ireland, 1983b:6]

According to Acton (1997: 45) while the words changed, the fundamental ideas of the State in relation to the 'Traveller problem' did not and although discrimination, prejudice and hostility towards Travellers was given prominence in the report, racism was not named as a fundamental issue. In its conclusion, the Review Body reported that it was satisfied that it did not have evidence to indicate the occurrence of discrimination against Travellers in accessing State entitlements, including social welfare payments and enrolment in schools. It did, however, report that there were many cases of 'bias' against Travellers in the allocation of tenancies by local authorities. In considering ‘special legislation’ to outlaw discrimination against Travellers, the Review Body reported that “implementation of such legislation would be fraught with many difficulties, especially in the absence of a precise legal definition of “traveller”. Accordingly, the enactment of anti-discrimination laws is not sought” (Government of Ireland, 1983b: 35).

A key influence on the Review Body and policy in relation to Travellers during this period was the contribution of Patricia McCarthy (1972) in which she rejected Traveller ethnicity, and instead, argued that Travellers were a “sub-culture of poverty.” McCarthy derived her analysis from the work of anthropologist Oscar Lewis (1963, 1966) who sought to account for the persistence of urban poverty amongst those with the “lowest income level and the least education” in Mexico. In his work, Lewis attributes this phenomena to a “culture of poverty” which is an “adaptation and a reaction of the poor to their marginal position in a class-stratified, highly individuated, capitalistic society.” (21) Lewis argues that the values and attitudes of the culture of poverty culture is internalised at a young age and perpetuated, therefore leading to a continuous cycle of poverty. As he notes:

> The way of life which develops among some of the poor under these conditions is the culture of poverty. It […] can be described in terms of some seventy interrelated social, economic, and psychological traits […] Once the culture of poverty has come-into existence it tends to perpetuate itself. By the time slum children are six or seven they have usually absorbed the basic attitudes and values of their subculture. Thereafter they are psychologically unready to take full advantage of changing conditions or improving opportunities that may develop in their lifetime. [Lewis, 1966: 21]

Lewis goes on identify seventy objective traits which characterise a culture of poverty. These traits includes the lack of effective participation and integration of the poor in the major institutions of the larger society, poor housing conditions and the absence of childhood. Some other traits include strong feeling of marginality, helplessness, dependence, and inferiority. Using Lewis’ culture of poverty theory as a starting point, McCarthy (1972) reductively argues that Travellers’ patterns of economic and family life, child rearing practices, social controls and skills acquisition aligns with the criteria as set out by Lewis, and in rejecting Traveller ethnicity, she argues:

> It is a basic assumption of this study that the Irish travellers […] do not constitute a separate ethnic group with an entirely separate tradition and culture. Poverty is considered to be basic to the problem of itinerancy in this study. [McCarthy, 1972: 17]

While McCarthy has since repudiated this view, at the time, her analysis was particularly influential for both researchers and policymakers, most notably the Economic and Social Research Institute (1979) which argued:

> We are convinced that itinerancy is a problem and an aspect of poverty; that educational deprivation is acute, that movement into settled society is what the majority of itinerants themselves want. [ESRI, 1979: 39]

This analysis also informed the Review Body, which intensely focused its efforts on Traveller settlement. This is clearly demonstrated in the recommendations and plans for accommodation which placed an obligation on local authorities to provide accommodation to Traveller families either in the form (1) standard housing, (2) Traveller-specific group housing; or (3) serviced [permanent/official] sites. This led to the policy of 'sharing out the [Traveller] problem,' resulting in each local authority being tasked with 'housing' Travellers within their geographic boundary. According to Collins (1994) and Pavee Point (2005a), the basic approach to the Review Body's accommodation proposals was towards "controlling, if not ending, Travellers' mobility" (38). This is evidenced in its statement concerning the accommodation of young Travellers, "young people marrying from houses should be dealt with as settled people even if they have to live in trailers for some time (45). While not as explicit as the Commission report, this statement reflects a clear assimilationist attitude amongst the Review Body, that a mere shift of accommodation, in this case, Travellers moving from a trailer to a house would result in Travellers ceasing to be Travellers, essentially 'becoming settled,' and thus addressing this subculture of poverty. This flawed analysis was predicated on Travellers' identity as solely rooted in poverty as suggested by McCarthy (1972), and by proxy, accommodation. Spatial movement or nomadism was perceived as problematic, and similar to the Commission, the Review Body developed a clear strategy to eradicate Traveller identity by "putting an end to nomadism" by giving Travellers the option of either bricks and mortar (standard accommodation and group housing) or permanent fixed sites (Collins, 1994; Pavee Point, 2005a).

Furthermore, similar to the Commission report, Traveller women were put forward as the key actors in justifying State settlement. Settlement advocates, who were largely comprised of female religious workers, frequently made their case for 'settling' Travellers through the provision of permanent accommodation in maternalist terms (Helleiner 2000[1961]: 167). Advocates pointed to poor and unsanitary living conditions of Traveller mothers and children on halting sides, insisting that permanent housing, comprised of bricks and mortar, would ensure a secure environment for their children and improve the health status of the family (Helleiner 2000[1961]: 167). This assurance was frequently reiterated in the Review Body as they observed:

> It is clear from the health board replies that a great deal of ill health among travellers is associated with the overcrowded caravans and insanitary conditions in which many families live […] The Review Body is satisfied that even the best-appointed caravan is not suited as permanent accommodation for a large family, particularly in the Irish climate. The overcrowding, lack of proper sleeping accommodation, poor ventilation, and condensation associated with a large number of people living permanently in a caravan are unacceptable by today's standards. In the opinion of the Review Body they pose a continuing hazard to the health of the occupants. The Review Body accepts that many travellers wish to continue to live in caravans but it must point out the danger to health, particularly to that of the children, associated with this form of accommodation. [Government of Ireland, 1983b: 95-96]

Traveller women’s perinatal health also featured as a key issue for the Review Body as they indicated concern in relation to high fertility rates, poor maternal health and the high rates of Traveller infant mortality. This was also raised in the Commission report in 1963, with a key recommendation to resource health visits to sites to encourage Traveller women’s engagement with maternity services and uptake of childhood vaccinations. While the Review Body concurred with the Commission in continuing to encourage engagement with maternity services, it also recommended family planning services for Traveller women, advising that “health boards should, as a deliberate policy, provide special care and advice for Traveller women in family planning that is sensitive to their way of life” (Government of Ireland, 1983b: 97). This recommendation was operationalised through the establishment of Traveller mobile health clinics. One of the first clinics was located in Dublin region in the Eastern Health Board, serving Traveller women and their young children in the catchment area. The clinic provided medical prevention services and health education, in addition to contraceptive information for Traveller women (Rigal, 1993). However, according to Fay (cited in Kavanagh, 2018) this approach effectively created a segregated service for Travellers, as Traveller women began to use the mobile clinics as a way of accessing primary care. While not an intended outcome of the mobile service, it further marginalised Travellers from mainstream health services.

It has been argued that this State-sponsored endeavour was simply another element in the government’s broader political project of economic and ‘social modernization’ of Travellers, as fertility began to slowly conform to more of non-Traveller model of ‘appropriate’ family size (Helleiner 2000[1961]: 26; Kavanagh, 2013; Kavanagh, 2018). It was also in this context that Traveller fertility was targeted as a ‘development area’ by the State and thus, following the legalisation of contraception in the early 1980s with the enactment of the Health (Family

Planning) Act 1979, family planning for (married) Traveller women emerged as priority for the Irish government.[97] Whilst not specifically documented to any extent[98] by research, there are reports which suggests that women, including Traveller women, were strongly encouraged to undergo sterilisation by medical professionals during this time, particularly those whom were perceived to have too many children (Helleiner, 2000[1961]): 211; Kavanagh, 2018).

3.5 Report of the Task Force on Travelling People: integration to interculturalism

Both the Commission and the Review Body reports reflected a prominent analysis of Travellers as deviant and non-conforming. While the Commission explicitly expressed its desire to assimilate and absorb Travellers into the general population, the Review Body utilized nuanced discourse or 'fuzzy terminology' (Liégeois, 1994; Kenny, 1997) to soften the impact of its assimilationist approaches and policies. In the interim periods between the Commission and Review Body, Ireland experienced notable shifts in social policy with the accession to European Economic Community in 1973 and subsequent transposition of equality legislation into national laws.[99] Ireland also ratified the UN Convention on the Elimination of All Forms of Discrimination Against Women and experienced a moved towards a more progressive reproductive and sexual health policy, with legalisation of contraception.

This period also distinctly marks the early development of community work[100] with Travellers and the emergence of Traveller leaders to drive campaigns aimed at State recognition of Traveller rights and identity values and principles underpinning Irish community work (Fay and Crowley, 1989; DTEDG, 1992; O'Connell, 1996, 1997; Harvey, 2013). Clearly identifying discrimination and racism as the core issue for Travellers and community development as the key method to create conditions for addressing it groups such as the Dublin Travellers Education and Development Group (DTEDG) (later 'Pavee Point Traveller and Roma Centre') and challenged dominant perceptions of Travellers as projected by State discourse and policy

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[97] Although interest in Traveller women's fertility appeared as early as the 1960s, with the Commission on Itinerancy, devoting a section of their report to Traveller fertility (Government of Ireland, 1963).

[98] Helleiner (2000[1961]) refers to Traveller women who disclosed that they were "privately encouraged by medical personnel to use contraceptives and/or after the birth of several children, to undergo sterilization" (211).

[99] Legislative changes such as the Anti-Discrimination [Pay] Act (1974), Maternity Protection of Employees At (1981), the repeal of the Civil Service (Employment of Married Women) Act (1973) and the Employment Equality Act (EEA) which although further aligned EU law with the Irish constitution permitting access to employment for men and women irrespective of gender or marital status, it only applied to women already participating in the labour market (Cousins, 1995). Further, the definition and measurement of unemployment in Ireland is quite problematic as it omits women who may be actively seeking and available for employment but are not eligible to claim unemployment benefits.

[100] Community development and community work are used interchangeably in this study. Adapting their definition from Pobal (1999), Community Work Ireland (2016: 5) define community work as, "a developmental activity comprised of both a task and a process. The task is social change to achieve equality, social justice and human rights, and the process is the application of principles of participation, empowerment and collective decision making in a structured and co-ordinated way."

(O’Connell, 1996, 1997). They also confronted the status quo and associated methods of working ‘for’ rather than ‘with’ Travellers as they embedded a community development approach and its underpinning principles of empowerment, participation and collective action into their core work (O’Connell, 1996, 1997).

According to O’Connell (1996, 1997) and Fay (cited in Kavanagh, 2018), this approach was strongly contested by local committees and professionals who had used social work to engage with Travellers; this relied heavily on a behavioural analysis which individualised both the problems and the solutions. Instead, Traveller organisations utilised a collective and social analysis, moving beyond simply responding to symptoms to identifying and to address the causes of discrimination, exclusion and poverty. Reflecting on the emergence of Pavee Point, O’Connell (1996, 1997) notes that the previous charity model employed by committees was disregarded in favour of a human rights-based approach underpinned by community development principles of empowerment, participation and collective action. Central to the organisation’s analysis were the concepts of racism and ethnicity and the importance of Traveller participation and identity in the development for policy.

This work laid the foundations for the emergence of Traveller organisations. Support was given to initiatives using a community development approach to address discrimination and realise Traveller rights using European and national funds. It is within this context that Traveller organisations began to develop throughout the country – in Galway, Donegal, Limerick and elsewhere – and thus a strong Traveller infrastructure began to emerge and take shape (Fay and Crowley, 1989; O'Connell, 1996; Fay, 2018; Kavanagh, 2018). In 1993, Pavee Point successfully lobbied for inclusion of commitments to address Traveller issues in the Programme of the incoming Government. This, along with successful solidarity among new Traveller projects and Traveller leaders resulted in the formation of the *Task Force on the Travelling Community* (Government of Ireland, 1995).

Generally considered as a ‘watershed moment’ in Traveller focused policy, the Task Force radically shifted its analysis and conceptualisation of Travellers, moving from a ‘sub-culture of poverty’ framework to one of cultural rights (Fay and Crowley, 1989; O'Connell, 1996, 1997; Fanning, 2009). The Task Force was established under the auspices of the Department of Equality and Law Reform and unlike the Commission and Review Body, Traveller representatives and national Traveller organisations actively participated in and shaped both the inquiry and subsequent policy recommendations of the final report. The terms of reference also reflected a clear shift in the State's conceptualisation of the 'Traveller problem,' initially from deviancy and cultural inferiority (Commission on Itinerancy), to nomadism and lack of adaption to settled ways (Review Body), and finally to discrimination resulting from hostility against Travellers by the settled population (Task Force). The role of the State in contributing to Traveller discrimination was also recognised through the acknowledgement of institutional discrimination.

The language of the Task Force Report shifted dramatically and it was the first time that government policy acknowledged Traveller ethnicity, albeit ambiguously, by recognising the distinctiveness of Traveller culture and collective identity:

> The Traveller culture lies in the values, meanings and identity that the Traveller community shares. It is clear that the Traveller community' culture is distinct and different […] Traveller nomadism, the importance of the extended family, the Traveller language and the organisation of the Traveller economy all provide visible or tangible markers of the distinct Traveller culture. [Government of Ireland, 1995: 5]

The terms of reference were also starkly different from the previous reports as it sought to advise on the needs of Travellers and on Government policy and to make recommendations to ensure appropriate and "co-ordinated planning is undertaken at national and local level in the areas of Housing, Health, Education, Equality, Employment, Cultural and anti-discrimination areas" (Government of Ireland, 1995: 67). This reflected a holistic approach to Travellers as intersecting issues were examined and key recommendations proposed on cultural identity, accommodation, disability, health, economy, participation, discrimination and gender. The latter recognised the heterogeneity and the important role of Traveller women within the community and through the application of an intersectional analysis, acknowledged the impact of institutionalised violence, discrimination and racism on Traveller women.

While the report acknowledged gaps in health status, it did not focus solely on Traveller women's reproductive and/or maternal role. Instead, the report was underpinned by gendered analysis and it made key recommendations in relation to gender equality. This included recommendations for Traveller women's economic roles, with specific reference to targeted measures such as the Primary Health Care for Traveller Projects (PHCTPs) to enhance professional development of Traveller Community Health Workers and creating the necessary conditions for economic independence and gender equality. This was informed by the work of the National Traveller Women's Forum (NTWF), established by Pavee Point in 1988 as a result of collective issues emerging from Traveller women participating in training programmes[101] and the growing need for a gendered focus on equality for Traveller women, both internal and external to the community (O'Connell, 1996, 1997; Fay and McCabe, 2015). According to McDonagh (2013: 13):

> Racism was named and acknowledged as a reality for Travellers. Understanding women's human rights, pulling and stretching the cultural boundaries was all part of the principles of community development. Traveller organisations such as Pavee Point were creating safe spaces where sensitive issues such as domestic violence, feuding, drug misuse could be discussed within the community.

It was also a mechanism to develop further relationships and solidarity with other Traveller organisations, strengthening the Traveller infrastructure. The NTWF was the first national network of Traveller women and Traveller women's organisations to adopt an intersectional gendered analysis to their work and to use a human rights based approach. The organisation is underpinned by community development principles with a key objective of realising Traveller women's full gender equality by supporting them to take leadership roles within their own and the wider community (NTWF, 2017).

The Task Force report was widely endorsed by Traveller organisations and government departments. The report was significant as it informed national-level policy making and legislation in relation to Travellers. Novel in its approach, the report emphasised the need for mainstreaming, targeting and participation of Travellers in all policy areas. Soon after publication, an Inter-Departmental Working Group was established to consider its implementation as per the recommendations of the report, and due regard was given to composition of the group, including gender and ethnicity.[102] In 1996, the Government accepted most of the proposals of the Inter-Departmental Working Group and announced the Government's strategy in relation to Travellers which included:

- A 5-year National Strategy for Traveller Accommodation to be put in place by the Minister of State at the Department of the Environment;
- The introduction of legislation to give effect to the National Traveller Accommodation Strategy including amendment of the Housing, Planning and Local Government Management Acts;
- The establishment of a special unit in the Department of the Environment to monitor the National Traveller Accommodation Strategy, as well as a National Traveller Accommodation Consultative Group;
- A commitment to strengthen Health and Education services for Travellers;

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[101] This refers to training programmes rolled out by the Dublin Travellers Education and Development Group (now Pavee Point Traveller and Roma Centre).

[102] The Task Force report acknowledged the, "right of Travellers to a presence on the Board […] the Ministers concerned should ensure appropriate balances on the Board in terms of gender and of Travellers/Settled' people" (Government of Ireland, 1995: 31).

- A commitment that the Task Force recommendations would be taken into account in preparing Employment Equality and Equal Status Legislation; and
- The transfer of responsibility for Senior Traveller Training Centres from the Department of Enterprise and Employment to the Department of Education.

This strategy resulted in administrative[103] and legislative measures which were necessary to implement some of the Task Force recommendations, including the establishment of the Traveller Health Advisory Committee (THAC), the Traveller Health Advisory Forum and Traveller Health Units (as discussed in Chapter One). It also resulted in the introduction of equality legislation which specifically named Travellers as a protected group under equality grounds,[104] giving a "precise legal definition of Traveller," which was an issue raised by the Review Body in 1983 (Government of Ireland, 1983b: 35). This period was also critical as it laid the foundations for the first National Traveller Health Strategy (Department of Health and Children, 2002) and later the *All Ireland Traveller Health Study* (ATHS) (AITHS Team, 2010a, 2010b, 2010c).

Notwithstanding the THUs and the THAF, many of structures established as a result of Task Force no longer exist or are successfully functioning (See Appendix VIII). This is due to the lack of active participation and/or representation at departmental/statutory levels on such structures, leaving Traveller stakeholders at a stalemate. The loss of the THAC has had clear consequences for Traveller health inequalities as it was the institutional mechanism that ensured Travellers were included in national policy. It was specifically tasked to:

- Review and develop national policy for health strategies to improve the health status of the Traveller community;
- Ensure that Traveller health is a priority area within the Department of Health and Children and other relevant departments, and setting targets against which performance can be measured;
- Ensure coordination and liaison in the implementation of national strategies of relevance to the health status of Travellers;
- Ensure the coordination, collection and collation of data on Traveller health;
- Liaise with the HSE and the Traveller Health Units to improve Traveller health, access to health services and equity of outcomes in line with national policy, and;
- Provide a forum for the discussion of health initiatives for Travellers and for ongoing consultation with Travellers and Traveller organisations on health service delivery to Travellers.

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[103] This includes the establishment of the National Traveller Accommodation Consultative Committee (NTACC) and a Traveller Accommodation Unit in the Department of the Environment and Local Government; the enactment of the Housing (Traveller Accommodation) Act, 1998 which includes a requirement for five-year local authority Traveller accommodation programmes; the establishment of an Advisory Committee on Traveller Education the publication of the *Report and Recommendations for a Traveller Education Strategy* (Department of Education and Skills, 2008).

[104] This refers to the Employment Equality Acts (1998-2015) and the Equal Status Acts (2000-2015).

In terms of financial transparency, the THAC also had oversight on the Department's allocation of Traveller health budgets. Following the establishment of the HSE in 2006, Traveller budgets were transferred to the HSE, resulting in two significant changes to the functioning of THAC, with funding for Traveller Health Units becoming the responsibility of the HSE and the THAC no longer having any involvement in this. Traveller organisations contend that the absence of THAC has weakened opportunities to mainstream and prioritise Traveller health within the Department of Health in relation to funding, policy developments, and emerging health structures (Fay, 2018). THAC has not met since 2012, despite calls from Traveller organisations and a number of commitments made by the current Minister for Health, Simon Harris.

According to Fay (2018), while the Task Force was successful in achieving a change in rhetoric, this was not translated into the practice of many public services and policy makers, resulting in very little action or positive outcomes for Travellers on the ground. This was also noted in the Monitoring Committee in their progress reports as they highlighted the lack of progress in key policy areas. According to Niall McCutcheon, the Chairperson of the Committee (Department of Justice Equality and Law Reform):

> There has been a lack of adequate progress at local level, approximately one quarter of all Travellers live out their daily lives in difficult conditions […] We cannot continue to have the Traveller community treated as an underclass and have them deprived of the rights enjoyed by other Irish people. There is a continuing need for a strong policy commitment to Traveller issues if outcomes are to be achieved for the Traveller community. [Department of Justice and Law Reform, 2000: iv]

Established three years after the publication of the Task Force Report (Government of Ireland, 1995), the National Task Force on the Travelling Community Monitoring and Implementation Committee ('Task Force Monitoring Committee') was tasked with coordinating, overseeing and progressing the implementation process. Its terms of reference were clear (Department of Justice and Law Reform, 2000):

1. To co-ordinate and monitor the implementation of the recommendations on the Report of the Task Force on the Travelling Community which have been accepted by the Government or by Ministers;
2. To draw up and submit to the Government from time to time, starting in 1999, a progress report on the implementation of the recommendations including proposals for acceleration or prioritisation of implementation of recommendations;
3. To re-examine recommendations where necessary in the light of changes in Government policy and practice and of legislative, demographic, social and economic change, and:

4. To serve as a forum for consultation on current issues of national importance affecting the Travelling Community.

Comprised of Traveller representatives, social partners and departmental officials, the Committee was initially chaired by a Principal Officer from the Department of Justice, Equality and Law Reform, but Traveller organisations lobbied for an independent chair to ensure a fair and transparent process. Although the Committee monitored the Strategy's progress, it failed in driving its implementation. In its progress reports, the Committee acknowledged that improvements were slow in the absence of a national driver. While it was assumed that the Committee would undertake this role, it did not have the power to develop or implement policy. In its second and final report, the Committee highlighted the need for strong policy commitments and implementation if positive outcomes are to be achieved for Travellers.

3.5.1 What can be learned from this period?

This period marked a seismic policy shift in relation to Travellers. It reflects the explicit inclusion of Travellers in equality legislation and the development of a strong Traveller infrastructure, with three national Traveller organisations working collectively in solidarity. It also marks a broader shift to working with Travellers, moving away from a charity model to a community development and human rights-based approach. Fay (2018) notes that the broader context of community development work and the emergence of national social partnership in Ireland also created the opportunity to lobby for the formation of the Task Force and for implementation of its recommendations. It is also within this context that Ireland received external pressure from European Institutions and UN Monitoring Committees in relation to Travellers, with Pavee Point directly lobbing on international levels to ensure the inclusion of Travellers in their State reports (O'Connell, 1996, 1997).

Another key development during this period was the inclusion of the ethnicity/cultural background question in the national census which was considered a significant achievement as it provided a clear evidence base to inform the development of policy not only for Travellers but also for other minority ethnic groups.[105] The inclusion of the ethnicity question was the

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[105] Prior to the 2006 census, Travellers were the only ethnic group recorded in the national census. First through a proxy-based question for enumerators in 1996 and a Traveller-specific question in census 2002. Following an extensive public consultation and piloting, in 2006, the CSO introduced its ethnicity/cultural background question. The question was perceived as a compromise by Traveller organisations, with the addition of the word 'cultural,' as Traveller ethnicity was not recognised by the Irish State at the time. Additionally, while Traveller organisations understood the 'ethnic/cultural background' question would evolve to reflect the changing ethnic composition of the Irish population, this has not been the case. Census 2016 was unchanged from the previous one in 2006, with the exception of one question recognising the legal status of same-sex marriage. The CSO has indicated that census 2021 will be "a change census' and invited submissions on the content of the questionnaire for the 2021 census during a public consultation in 2017. The CSO also convened a Census Advisory

result of collaboration between Pavee Point and the National Consultative Committee on Racism and Interculturalism (NCCRI) (Kavanagh, 2016). However, it is also a result of lobbying efforts to ensure that a number of recommendations related to disaggregated data were included in the Task Force Report, which effectively provided the impetus for the Central Statistics Office to include an ethnicity question. This had a substantial impact on other State agencies and services as an ethnicity question has been incrementally introduced to other data collection systems, including prisons, probation, education, social inclusion, drugs and health services (Kavanagh, 2016). Fay (2018) notes that there was much more potential in this period for further equality and human rights work as there was clear political will and leadership and willingness to work in partnership with Traveller organisations as part of National Social Partnership arrangements through the Community and Voluntary Pillar. However, this was later diminished in the context of austerity, including the dismantling of the equality sector and disproportionate cuts to Traveller organisations and the *de facto* side-lining of Social Partnership with the economy being government priority (Harvey, 2013; Fay, 2018). With the exception of Harvey (2013), much of this work remains undocumented within academic scholarship, but it is integral to the overall understanding of the Traveller policy landscape and in giving visibility to the work of Travellers and Traveller organisations in their role of actively shaping and shifting policy.

3.6 Towards inclusion?

O'Connell (1996, 1997) asserts that Irish state policies affecting Travellers can be divided into the following three distinct phases which are linked to specific policy documents outlined in the sections above:

1. The assimilation phase (Report on the Commission on Itinerancy in 1963);
2. The integration phase 1980–1990 (Report of the Travelling People Review Body in 1983), and;
3. The intercultural phase 1990 – ongoing (Report of the Task Force on Travelling People in 1995).

Drawing on O'Connell's initial analysis, this research proposes that Ireland is entering a new phase, albeit rudimentary, in the State's relationship with and policies affecting Travellers. The 'inclusion phase' was initiated in 2017 following the State's acknowledgement of Traveller ethnicity and the publication of the new National Traveller and Roma Inclusion Strategy

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Group (CAG) and a number of subgroups, including one on ethnicity of which Pavee Point was a member. The ethnicity subgroup agreed to pilot two variant questions, both inclusive of Roma. The Census Pilot Survey was conducted in September 2018 and the results of the pilot are expected to published in 2019 (CSO, 2018a, CSO, 2018b).

(NTRIS) (2017–2021). The NTRIS was launched in 2017 after its precursor, the National Traveller/Roma Integration Strategy (2011) failed to meet the European Commission's implementation progress reports for five years in a row (European Commission, 2012, 2013, 2014, 2015, 2016, 2017). Ireland was obliged to develop this Strategy as Travellers are targeted under the EU Framework for National Roma Integration Strategies (NRIS) up to 2020. This creates obligations for the Irish State to include Travellers and Roma in all relevant strategies, which address the inclusion of vulnerable and marginalised groups. NRIS has a strong economic and social focus, requesting all Member States, including Ireland, to develop and implement dedicated long-term strategies to promote Roma integration in four key areas: access to education, health care, employment, and housing and essential services. It also seeks to allocate sufficient targeted resources to achieve progress. Ireland's first National Traveller Roma Integration Strategy (Department of Justice and Equality, 2011) was developed without the active consultation and participation of Travellers and Roma, and did not contain goals, targets, indicators, time frames, funding, monitoring and evaluation mechanisms (Department of Justice and Equality, 2011; Pavee Point, 2014). It contained no reference to Roma, and/or to gendered needs of Traveller and Roma women. Overall, the Strategy was met with scrutiny by the European Commission, and Ireland's annual assessments by the European Commission (2012, 2013, 2014, 2015, 2016, 2017) were extremely poor, with the 2012 assessment reporting that Ireland had met only four out of twenty-two criteria. This assessment also raised serious concerns about the lack of targets, detail, consultation and funding mechanisms (European Commission, 2013).

3.6.1 National Traveller Roma Inclusion Strategy

In 2015, the Department of Justice and Equality (DJE), in response to Traveller organisations, re-evaluated its National Traveller/Roma Integration Strategy recognising the need for a robust and meaningful approach to the EU Framework. Consequently, a national consultation process was undertaken throughout 2015–16, with support of Pavee Point. The consultations included Travellers, Roma and Traveller organisations and agencies working with Roma. It also involved all Government departments and a range of statutory agencies. Given the historical context and assimilative connotation associated with the word 'integration,' Pavee Point and other local Traveller organisations lobbied the DJE to amend the name of the strategy and consequently, Ireland's revised strategy is the National Traveller and Roma Inclusion Strategy. Similar to the Task Force Report, Traveller organisations had a prominent role in shaping the actions contained in the Strategy, but there were compromises as the Strategy involved a number of government departments. Launched in 2017, the NTRIS[106] contains 149 actions across ten cross-cutting thematic areas,[107] including health and gender equality. A traffic light system to monitor progress under each action has been developed (Department of Justice and Equality, 2017). Relevant Departments are required to report to the Department of Justice and Equality on their progress using this system. Again, similar to the Task Force Report, Traveller organisations have endorsed NTRIS as the new policy roadmap for Travellers and Roma in Ireland. In the foreword, the Minister of State, David Stanton, acknowledged:

> Travellers and Roma are among the most disadvantaged and marginalised people in Ireland. During the years of the financial crisis from which Ireland is emerging, those at the margins of our society frequently-and regrettably-suffered disproportionately from the effects of financial adjustments. Now that Ireland's economy is back on a firmer footing, it is a moral and societal imperative that we work together to address the real needs of these communities [Department of Justice and Equality, 2017:3]

However, the Minister's comments have not resulted in any real investment by the State. Two budgets after the launch of NTRIS there were still no additional resources allocated to its implementation, despite the disproportionate cuts to Traveller services throughout austerity (Harvey, 2013). Traveller organisations have consistently highlighted the need for an adequate budget to implement NTRIS; the Department of Justice and Equality has responded by committing to an additional €500,000 to 'Traveller and Roma Initiatives' in 2019 (Department of Justice and Equality, 2018).

Furthermore, a NTRIS Steering Group was established by the Department of Justice and Equality in April 2015 with a mandate to contribute to developing NTRIS and to monitor the implementation and progress of NTRIS. Similar to the Task Force Steering Group, the aim is to foster inter-Departmental and cross-sectoral working. Chaired by the Minister of State for Equality, Immigration and Integration, the group is comprised Department officials across relevant Departments and Traveller and Roma organisations. However, the group does not function effectively at present, it meets four times per year which presents key challenges in driving implementation. Additionally, while funding has been allocated for 2019, the strategy overall does not have a dedicated budget and there is a lack of transparency around allocated funding and actual spend.[108] The strategy does not have clear impact indicators and allows for

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[106] NTRIS is the first national policy framework to explicitly include Roma as a key focus, however, actions in relation to Roma are seriously lacking. Accommodation for instance does not contain one action in relation to Roma.

[107] These include: cultural identity, education, employment and the Traveller Economy, children and youth, health, gender equality, anti-discrimination and equality, accommodation, Traveller and Roma communities, public services .

[108] According to Pavee Point (2018: 10), in 2016 the NTRIS Steering Group were informed that €1 million in new funds would be allocated for the implementation of the Strategy in 2017 (€800,000 for Traveller initiatives and €200,000 for Roma initiatives). However, in 2017 the Steering Group was informed that no further money will be available from the Department of Justice and Equality in 2018 and the strategy will be implemented from funding from Departments. Data on the funding available from Departments is not available as of yet .

actions to be used to indicate progress when it is not clear that actual progress has been made. In the absence of impact indicators and an overall monitoring and evaluation framework, Traveller and Roma organisations remain concerned that the existing monitoring of the strategy will be a "paper exercise, bearing little relation to improvements or disimprovements on the ground" (Pavee Point, 2018: 10). It is in this context Travellers and Traveller organisations remain frustrated, and are concerned that "yet another policy document with the potential of affecting real change may merely be lip service on the part of the State to meet basic European requirements to ensuring Traveller and Roma inclusion" (Kavanagh, 2018).

3.6.2 National Traveller Health Action Plan

Moreover, a key action from NTRIS is the development and implementation of a "detailed action plan, based on the findings of the All Ireland Traveller Health Study, to continue to address the specific health needs of Travellers, using a social determinants approach" (DJE, 2017). In 2018, a discussion paper outlining a draft framework for an effective National Traveller Health Action Plan (NTHAP) was developed by the HSE National Office for Social Inclusion and published in advance of four regional public consultations (Watt and Kavanagh, 2018:3). A range of stakeholders attended the regional consultations, including representatives from local and national Traveller organisations, Traveller Health Units (THUs), health stakeholders, accommodation, children/youth representatives and education stakeholders. While the draft framework was discussed in relation to the local/regional context, a number of key issues were identified as being essential to the success of the NTHAP. This included the establishment a new agency, a Planning Advisory body for Traveller Health (PATH) which would drive implementation of Traveller health policy. This proposed new body would merge the roles of THAC and THAF and would have representation from Traveller organisations; the HSE; Department of Health; Traveller Health Units; Primary Health Care for Travellers Projects; and the Department of Department of Housing, Planning and Local Government. The NTHAP is scheduled to be launched by the end of 2018. While a draft plan was submitted to the Department of Health by the HSE National Office for Social Inclusion, objections from the Department to the establishment of the Planning Advisory body for Traveller Health (PATH) due to resource implications has placed a pause on progressing the plan further. According to Fay (2018: 7), "in the absence an institutional mechanism to drive implementation, the plan is effectively doomed from the outset."

3.6.3 A new era?

While both NTRIS and State acknowledgement of Traveller ethnicity are key milestones which mark a transition in official discourse and policy in relation to Travellers; they also demonstrate a commitment to working in partnership with Travellers. In his foreword to NTRIS, David Stanton, Minister of State for Justice at the Department of Justice and Equality with special responsibility for Equality, Immigration, and Integration reflects:

> I am proud to say that it heralds a new era for Traveller and Roma inclusion in Ireland […] symbolic gesture will create a new platform for positive engagement by the Traveller community and the Government in together seeking sustainable solutions based on respect and an honest dialogue [Department of Justice and Equality, 2017: 4-7].

This phase of inclusion is ongoing; it should not be naively understood as marking the end of Traveller exclusion, marginality and discrimination in Ireland. As McDonagh (2017) observes, "acknowledgement of our minority ethnic status represents a serious ideological shift from the Ireland of my youth […] we understand acknowledgment of our ethnicity will not be a panacea for Traveller inclusion in Ireland. However, it is a key milestone on our path towards inclusion" (para 6-14). McDonagh's reflection has been reiterated by Traveller and allied non-Traveller activists, who, despite expressing frustration at the lack of implementation and delivery of policy commitments, remain defiant in their optimism of an inclusive Ireland where Traveller human rights are respected, protected and fulfilled.

3.7 Conclusion

This chapter has served as a background to Traveller related policy in Ireland, focusing on the policies, practices, and outcomes of institutional racism and discrimination in relation to Travellers and Traveller women in Ireland. It has argued that the racialization of Travellers by the State has resulted in operations, interactions and patterns of subordination, including racism and discrimination based on gender and ethnicity, all of which are embedded in Irish institutions, legislation and policy. It has traced the development of Traveller policy in Ireland from assimilation, to integration to interculturalism and proposes that we have entered into a new phase of inclusion following the State acknowledgement of Traveller ethnicity and the publication of the National Traveller and Roma Inclusion Policy. Furthermore, this chapter has argued that given the right conditions, key equality and human rights achievements can be realised, but this requires partnership with Traveller organisations, investment and political leadership to drive policy implementation. The next chapter provides an empirical and theoretical discussion to contextualise the study, as such, I present the research to date on women’s experiences of pregnancy loss in Ireland. In addition, this chapter outlines some of the concepts that are relevant to the analysis of the data in this study.

Chapter 4

From the individual to the structural: considerations of intersectionality, structural racism and minority ethnic women's experiences of loss

4.1 Introduction

The previous chapters provided a contextual discussion to the substantial research area, including an overview of the key policies, practices, and outcomes of institutional racism[109] as they relate to Travellers, women and maternity care in Ireland. This chapter offers both an empirical and theoretical discussion to contextualise the study. In doing so it provides:

1. a synthesis of relevant scholarly work pertaining to the substantive research area of pregnancy loss drawing on critical literature from several related fields including: sociology; midwifery, medical anthropology of reproduction, analyses of pregnancy and motherhood; and geographies of death and dying; and
2. a conceptual framework for understanding key arguments set out in the previous chapter and subsequent chapters. First, this chapter begins by presenting a critical review of relevant research available on pregnancy loss, paying particular attention to the personal, interpersonal and structural dimensions of loss.

Next, this chapter introduces key concepts that are relevant to the analysis of the narratives presented in chapters ten and eleven. It is within this context that key concepts of intersectionality, structural violence, structural racism, gendered racism and obstetric violence are considered. These concepts are further discussed in relation to the data gathered and the particular interest of this study in Chapter 8. Given that this study is inductive, foregrounded in Traveller women's experiences, the concepts were derived from women's narratives during data collection and after extensive analysis in line with emergent findings.

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[109] See Chapter 1, Section 1.9.2 for a clear definition on institutional racism

4.2 Situating pregnancy and childbirth within academic scholarship

Both Oakley (1974) and Jordan (1992) contend that 'childbirth did not exist' in their respective disciplines, anthropology and sociology, prior to the 1970s. Historically,[110] studies on pregnancy and childbirth were situated within a traditional positivist medical model carried out primarily by those in biomedical sciences. This model stresses the pathologisation of pregnancy and childbirth as inherently biological processes which require medical supervision, intervention and surveillance (Martin, 2001a, 2001b; Kennedy, 2002). According to Davis-Floyd (1992: 28) implicit in this model are the assumptions:

> That the baby develops mechanically and involuntarily inside the woman's body, that the [male] doctor is in charge of the baby's proper development and growth, and that the doctor will deliver (produce) the baby at the time of birth.

As Davis-Floyd points out, the medicalisation of pregnancy and childbirth, that is the process whereby 'normal life events' (i.e. pregnancy and birth) become redefined as dysfunctional and unable to proceed without medical intervention or treatment (Purdy, 2001; Inhorn, 2007a, 2007b) has resulted in the objectification and fragmentation of women's bodies into components requiring medical expertise to ensure its smooth running. According to Rothman (1982) and others (see e.g. Martin, 1984, 2001a; Davis-Floyd, 1992) medicalised birth is underpinned by the 'ideology of technology' in which the unpredictability, inherent pathology and volatility of women's bodies (as defined by patriarchal medicine) is seen as conquered by obstetric technology and interventions. In biomedical terms, women's pregnant bodies are conceptualised as a faulty machine or "collection of parts" (Rothman, 1982: 35) which biomedicine can fix, improve and manipulate (Rothman, 1982; Martin, 2001a; Davis-Floyd, 2003). Biomedical research then was tasked with contributing to and informing these technical solutions.

This model remained dominant within scholarship into the 20th century, informing the maternity policies and delivery of maternity care, particularly in the West (Doyal, 1979; Kennedy, 2012). The substantive issue was subject to the 'sociological unimagination,' effectively relegated to margins of academia (Oakley, 1974; Ginsburg and Rapp, 1991, 1995, 2007; Greenhalgh, 1995; Davis-Floyd and Dumit, 1998). This was in part due to the historically dominant hierarchies of patriarchal power relations at the forefront of knowledge production which excluded women both as producers and subjects of knowledge (Rose, 1993; McNiven,

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[110] For a brief historical overview of the development of professional medicine in the field of childbirth see (Jordan and Davis-Floyd, 1993: 50-51).

2014, 2016). However, as Oakley (2016) describes, after decades of scholarly neglect, the infiltration of second wave feminism into the academy in the 1970s, "helped to nourish the sociological study of childbirth by querying particularly that division between the public and the private which had served so well to hide reproductive labour from the sociological gaze" (690). In effect, it offered a critique of the reductive approach to women's bodies, and urged social scientists to think "beyond established paradigms and procedures" (Davis-Floyd, 1992: xxii) by rejecting the pathologisation of women's experiences. As Jordan and Davis-Floyd note (1993:1), "birth is everywhere culturally marked and shaped" and therefore, could be studied, "behaviorally, socially, structurally, and historically, as well as normatively, dramatically" (Davis-Floyd and Sargent, 1992: ix). This approach dramatically reframed pregnancy and childbirth as *biosocial events*, recognising both the biological function and culture-specific social milieu within which women's biology is deeply embedded (Ehrenreich and English, 1973; Handwerker, 1990; Oakley, 1990; Jordan and Davis-Floyd, (1993); Inhorn, 1994; Ginsburg and Rapp, 1995; Greenhalgh, 1995; Staurt-Macadam and Dettwyler, 1995; Cecil, 1996a; Davis-Floyd and Dumit, 1998; Lock and Kaufert, 1998; Layne, 1999; Bentley and Mascie-Taylor 2000; Martin 2001[1987]).

4.3 Authoritative knowledge

As the field developed, so too did the scope of inquiry, with early research offering critiques of the pathologising of women's bodies, obstetric power and capitalist reliance on women's productive and reproductive labour (Martin, 2001a, 2001b). Others, focused their attention on the inherently political nature of reproduction and of research on reproduction (Ginsburg and Rapp, 1995). Researchers also became increasingly concerned with knowledge systems, ways of knowing about birth and how hierarchical gendered power relations became operationalised and reinforced in obstetric settings (Ginsburg and Rapp, 1991; Davis-Floyd, 1992; Jordan and Davis-Floyd, 1993; Martin, 2001a). Brigitte Jordan's (1992) influential work on childbirth heavily influenced this approach, with her concept of 'authoritative knowledge' emerging as a key framework for understanding the active suppression of women's embodied knowledge during pregnancy and childbirth. According to Jordan (1992), within any particular social situation, various understandings and ways of knowing exist, with some superseding others. Some "knowledge becomes discredited and devalued, while others become sanctioned, consequential, *official* and are accepted as grounds for legitimate inference and action" (Jordan, 1992: 1). It is the latter that gains dominance in what Jordan (1992) counts as *authoritative knowledge*.

Authoritative knowledge is not simply defined as the knowledge of people in authority positions, but it is the knowledge that is understood as *legitimate*, with individuals "not only accepting it (which is thereby validated and reinforced) but also actively and unselfconsciously engaged in its routine production and reproduction" (57–58). For example, in obstetric settings, successes are founded in science, effected by technology, and non-medical knowledge is devalued by all participants (professionals and non-professionals) including the pregnant woman who believes that actions and treatment proposed on the basis of professional medical knowledge is the best for her. It is in this context that authoritative knowledge is continually internalised, reinforced and reproduced through such hierarchical social interactions. This is further exacerbated in the context of structural inequalities, with one set of rules or form of knowledge gaining authority while at the same time devaluing and delegitimising others in doing so. In terms of Travellers, this takes on a specific connotation given historical experiences of assimilation, the denial and devaluation of Traveller ethnicity and racism, at institutional, individual personal and individual levels.

Moreover, as Jordan (1992) notes, non-conformity or subverting authoritative knowledge in some way carries the possibility of tangible sanctions including legal enforcement as evidenced in the phenomenon of court-ordered caesarean sections (Jordan, 1997; Chadwick, 2017b, 2018; Davis-Floyd, 2018). Drawing on these experiences, contemporary social science research, again, taking its cue from feminists, has re-centred its analysis on obstetric settings as sites of miscommunication, conflicted interpretations, and power struggles between women and health institutions (Jenkins and Inhorn, 2003). Recently emerging within the literature, this approach explores 'safe motherhood' through a rights-based approach to women's reproductive health, including respectful childbirth (Storeng and Béhague, 2014; Zacher Dixon, 2015; Davis-Floyd, 2018).

This has resulted in a diverse body of multi-disciplinary research from the fields of sociology, history, nursing, anthropology, geography, psychology and public health. These works challenge the medical model of pregnancy and childbirth by incorporating a social and cultural lens into their work, placing women's voices at the centre of analysis and focusing on their experiences as sources of power and subordination. Various topics have been explored, including: risk and birth, biological or 'natural' birthing bodies; women's conceptualisations of 'birth satisfaction,' medicalisation, choice and control, social support, intersectional issues and implications of mode and place of birth (Chadwick, 2017b, 2018). Early research in the field tended to present women's experiences homogenously, that is, as white, middle-class and Euro-American. However, a number of researchers, specifically feminists working within Black, Indigenous, queer and postcolonial theoretical traditions challenged this universalised conceptualisation of 'women.' In doing so, they argue that women occupy complex and dynamic social locations and that different aspects of women's social identity (e.g., race, ethnicity, indigeneity, gender, class, sexuality, geography, age, (dis)ability, immigration status, religion) as well as the impact of systems and processes of oppression and domination (e.g., racism, classism, sexism, ableism, homophobia) greatly influence reproductive experiences and outcomes (Crenshaw, 1991; Hill-Collins, 1994; Yuval-Davis, 1996). Nevertheless, there is a paucity of literature on these experiences; specifically, the experiences of minority ethnic women (including Traveller women), poor women, migrants, teens and single mothers, homeless women, women experiencing addiction(s) and incarcerated women. While there have been a number of recent developments in this regard[111], they remain disproportionately underrepresented within mainstream academic literature.

4.4 Pregnancy loss

According to Cecil (1996a, 1996b) and others (see e.g., Layne, 2003; van der Sijpt, 2007), pregnancy loss has not been considered a worthy subject of attention by the social sciences. Therefore, it remains on the periphery, rather than at the centre of social research. Early pregnancy loss scholarship, similar to that of the broader research on reproduction, was framed within a positivist tradition and usually comprised of quantitative studies using standardised measures (Stirtzinger, et al., 1999; Tsartsara and Johnson, 2006). Primarily carried out by psychologists and medical practitioners, this body of research general focused on the aetiology, prevention, treatment and management of loss. Research in this regard aimed to inform clinical practice in ensuring 'successful' pregnancy outcomes (Cecil, 1996a, 1996b; Lovell, 1997; Inhorn, 2003; Jenkins and Inhorn, 2003; Layne, 2003; Inhorn, 2007a, 2007b). Sinan-Jones (2010) argues that this has led pregnancy loss to be "sequestered both practically and theoretically by medical and psychological and other scholarly discourses of bereavement" (i). Layne (2003) notes that preoccupation with optimal outcomes has resulted in the unrealistic expectations of what biomedicine can actually deliver. As a consequence, this has

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[111] See e.g., Wojnar (2007); Wojnar and Swanson (2006); Peel (2009); Peel and Cain (2016)

systematically marginalised women whose experiences do not confirm to such 'linear narratives', as she notes:

> Foetuses that don't develop properly and babies that die challenge these cherished narratives about the natural course of individual development and, given its own linear progress, our assumptions about biomedicine's ability to assure that pregnancies and babies stay on this expected path. [2003: 68]

Social science scholarship in many ways contributed to this marginalisation as there has been reluctance to adopt pregnancy loss as a meaningful unit of analysis, let alone its focus. Notwithstanding the handful of scholars[112] who have placed pregnancy loss at the centre of their research, in general, where pregnancy loss exists within social research, it has been trivialised and given little prominence in the overall narrative or stories presented. This, despite, an estimated 30–40% of all pregnancies ending in loss (Cohain et al., 2017; Sapra et al., 2017; NICE, 2018; WHO, 2018a). Furthermore, where scholarship exists, it has been historically focused on the personal and interpersonal experiences of women in their interactions with partners, family members, health professionals, etc., often omitting a broader structural analysis beyond health systems and institutions.

4.5 Woman-centred discourse of pregnancy loss

Feminists posit that ongoing taboos surrounding death, failure, and women's biology coalesce, limiting social acknowledgement and support for pregnancy loss (Cecil, 1996a, 1996b; Layne, 1997; 2003). However, Layne (2003) compels feminists to also reflect on internal tensions and lack of inclusion of pregnancy loss within their research agendas. Layne argues that the realm of feminist scholarship on the topic of pregnancy loss "remains an orphan," with feminists abandoning their "sisters in hours need" at the behest of anti-abortion activists, who based their argument on the presence of foetal and embryonic personhood. Layne suggests that feminists have avoided pregnancy loss research precisely because it would imply or concede that such a presence exists. The rationale, therefore is that if one were to acknowledge that there was something of value lost, something worth grieving for, one would thereby automatically accede the inherent personhood of embryos and foetuses. This, she argues has "contributed to the shame and isolation that attends these events" and by doing so, feminists have relinquished the discourse of pregnancy loss to anti-choice activists (239). In an attempt to resolve this, Layne urges feminists to "acknowledge the frequency and importance of such events in women's lives," (239). As such, we must shift pregnancy loss from a private space of shame to a public

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[112] See e.g.,Oakley (1980; 2016); Oakley et al. (1990) Lovell (1983, 1997); Reinharz (1988a, 1988b); Becker (1994); Cecil (1996a, 1996b)

space of solidarity by contributing to the creation of a “woman-centered discourse of pregnancy loss” (239).

4.6 Key themes from the literature on pregnancy loss

4.6.1 Individual experiences

The small body of feminist research on pregnancy loss has provided valuable qualitative insights on women’s personal experiences, their interpersonal experiences and the social and institutional responses to loss and bereavement. Distinguished from positivist-oriented research, this body of literature focuses on the emotional and psychological aspects of loss for women, their partners and to an extent, other family members. Overall, the literature recognises pregnancy loss as a significant, and often traumatic event for women, their partners and broader family networks, regardless of the gestation (Layne, 2003; McCreight, 2004; 2007; Kersting and Wagner, 2012; McNiven, 2014, 2016; HSE, 2016a, 2016b). This reflects a considerable shift from earlier social and academic suppositions that a later gestational loss was ‘more significant’ with stronger and longer levels of grief, depression and anxiety than earlier losses (Toedter et al., 1988; Goldbach et al., 1991; Brier, 2008). Building on the work of Peppers and Knapp (1980), recent scholarship has focused on miscarriages in order to illuminate the subjective nature of loss and to combat the presumption that a shorter gestational period does not necessarily mean that the experience is any less profound (Letherby 1993, 2003; Layne, 1996, 2003, 2006a, 2006b, 2009; McNiven, 2014). The literature identifies women’s feelings of isolation, anger and abandonment, which contributes to their overall psychological and emotional responses. The literature also identifies the clinical environment as having a significant impact on a woman’s overall experience of pregnancy loss. Clinical environment in this context refers to doctors’ offices, maternity units and emergency rooms. Women report a mixture of interactions with health services, including those which have been perceived as supportive (e.g. providing validation and space to talk about their experience) and unsupportive (e.g. being dismissive of women’s emotions, isolated women after loss). These experiences, combined with a lack of information and/or clarity regarding follow-up, have resulted in women’s experiences of marginalisation and distress (Bellhouse et al., 2018).

Pregnancy loss grief is well established in academic literature and has been recognised in policy and service provision since the 1970s. However it is only recently that pregnancy loss has been identified as a potential stressor for psychological distress for women. This includes depression, anxiety, and for some women, post-traumatic stress disorder with symptoms persisting over a considerable period of time[113] (Athey and Spielvogel, 2000; Giannandrea et al., 2013; Nelson et al., 2013; Gold and Johnson, 2014; Gold et al., 2014). Women who have higher rates of pregnancy loss and/or have a history of poor mental health face a significantly higher risk in this regard. Other risk factors include, socio-economic status, social support and a history of trauma. Furthermore, this also links to feelings of isolation and lack of acknowledgement of the loss which is referred to as disfranchised grief (Doka, 1989, 2003; Smith, 2013).

However, as Brier (2008: 452) notes, the term 'grief' is often ambiguous and tends to be subjectively and inconsistently defined (Prigerson et al., 1999; Shaver and Tancredy, 2001). Disfranchised grief has been identified as a useful term to describe the particular grief that women and often, their partners feel after loss (Doka, 1989, 2003: Mulvihill and Walsh, 2013). As discussed in Chapter 2, historically the prohibitive practices by medical professionals, family, and wider community were detrimental to women following loss resulting in considerable suppression of memories and further compounding of grief (Cecil, 1994a, 1996a; McCreight, 2001, 2004; O'Connell et al., 2016). Doka (1989, 2003) argues that merely suppressing a woman's grief does not mean she will not grieve. On the contrary, the lack of social recognition of loss effectively excludes and 'disenfranchises' women from community support that might otherwise be extended following a bereavement. This is further exacerbated by the absence of public memorialisation and mourning. Disenfranchised grief, in this context is not merely unnoticed or forgotten, but is unacknowledged and deemed invalid by society. There is no public mourning or ritual for the loss, leaving women feeling unsupported (Doka, 1989, 2003).

4.6.2 Interpersonal experiences: intimate relationships

While partners remained largely invisible within early pregnancy loss scholarship, there has been a substantial recognition that loss can be distressing and traumatic for partners too (Saflund, et al., 2004; Sian-Jones, 2010). Very little has been written outside the experiences of heterosexual couples, an issue that has been highlighted by a number of scholars.[114] Where literature exists, it focuses on men, masculinity, loss and grief. Research indicates that social

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[113] While this varies from each individual, a longitudinal study of over 13,000 women in the United Kingdom conducted by Blackmore et al. (2011) found that women who had experienced previous pregnancy losses experienced persistent depressive and anxiety symptoms after 33 months. Previous research by research conducted by Beutel et al. (1995) also found that depression following miscarriage persisted for up to 1 year.

[114] See e.g.,Wognar and Swanson (2006, 2007); McManus et al. (2006); Renaud (2007); Peel (2009);

and cultural expectations of men assume that a man must be strong emotionally in order to support his partner, with men reporting that they feel blame; loss of identity; and the need to appear strong and hide feelings of grief and anger (Cook, 1988; Borg and Lasker, 1989; Layne, 2003; McCreight, 2004; 2007; McNiven, 2014). According to McCreight (2004) the perception that men have a limited role in pregnancy loss is unjustified, as it obscures men's experiences and "the meanings they attach to their loss, in what may be a very personal emotional tragedy for them where they have limited support available" (326). The literature also notes that women's intimate relationships also go beyond family members, with women seeking support from other women vis-à-vis support groups. This is documented in the work of Layne (2003, 2006a, 2006b, 2009) in which she examines the role of pregnancy loss support organisations as spaces in which women seek support and information from their peers. Contemporary analysis reflects a shift from traditional face-to-face support groups to online digital spaces whereby women seek out health information and general advice from their peers based on experiential knowledge (McNiven, 2014).

4.6.3 Interpersonal experiences: institutional relationships

Scholars have also recognised the impact of pregnancy loss on health staff, specifically midwives and nurses (Nash, 1987; Gwilliam, 1995; McCreight, 2005; Pastor Montero et al., 2011; Jonas-Simpson et al., 2013). According to McCreight (2005), nurses and midwives suffer grief and fear when dealing with the perinatal loss in a clinical setting and may not be able to cope with the emotions and distress of loss. McCreight suggests that nurses experience a mix of dilemmas and controversies when it comes to revealing their emotions to patients, noting that they work in a "milieu of contested understandings regarding what is considered to be a responsible professional approach to grief" (442). Drawing on this, Puia et al. (2013) identifies six themes from their research with nurses including: (1) getting through the shift; (2) symptoms of pain and loss; (3) frustrations with inadequate care; (4) showing genuine care; (5) recovering from traumatic experience; and (6) never forgetting. Puia et al. (2013) suggest that loss can have a lasting effect on health staff and recommend that support may be needed.

4.7 Intersectionality

This study centres upon Traveller women's experiences of pregnancy loss and in doing so, it attends to the personal, interpersonal and structural factors that mediate these experiences. Consideration of the historical, social, political, and economic position of Traveller women in this regard is critical to this endeavour. As a patriarchal society, Traveller women's experience in Ireland, similar to other women, is predicated on gender inequality, manifested in terms of misogyny and sexism. However, as outlined in Chapter 3, Traveller women's experiences in Ireland are also distinct; defined by historical and contemporary experiences of racism and discrimination on individual and collective levels. Intersectionality offers a conceptual framework for understanding the ways in which overlapping systems of oppression and discrimination that women face, based not just on gender but also ethnicity, sexuality, economic background and a number of other 'axes' (Crenshaw, 1989).

Historically, feminist theory and practice have not been "free of ethnic and class bias" (Crickley, 1992: 103). As such, minority ethnic women, including Traveller women, historically found themselves "rendered invisible initially within the Women's Movement and racism toward them continued in the struggle for universal liberation for the 'universal woman'" (103). As McDonagh (2000) points out, Traveller feminists have made a significant contribution to the feminist movement, but "because they are advocating for basic human rights for Travellers, their work is not valued enough to be considered part of the feminist movement" (237). Furthermore, early Irish feminist scholarship and antiracist policy discourse largely excluded Traveller women[115] precisely because both rested upon on a discrete set of experiences that did not always accurately reflect the interaction of ethnicity and gender. Consequently, Traveller women's experiences were often defined on the basis of *either* their gender ('as women') *or* ethnicity ('as Travellers'). This was further compounded by the State's refusal to acknowledge Traveller ethnicity, which by extension denied the existence of racism. This notion of racism was located in a colour paradigm, with McDonagh noting, "colourism was the only way to define Irish racism" (239). This is echoed by Crickley (1992) in response to Hill-Collins' (1992) who suggests that feminist theories promoted the notion of a reified universal woman who is "white and middle class (4)," with Crickley (1992) noting, "she might have added that such theories promote notions of women as sedentary and Western orientation" (103).

As discussed in Chapter 3, the consideration of Traveller women's experiences in this regard was initially developed by Traveller organisations. Identifying discrimination and racism as a collective issue for Travellers, the National Traveller Women's Forum's (NTWF) focus on gender added an additional dimension to this overall analysis by recognising the unique forms

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[115] Alongside other women, including deaf women, disabled women, and LGBTQI+ women (Clare, 1999; Kwiotek, 1999)

of discrimination across multiple identities. As they assert, “Traveller women experience three-fold oppression and racism […] at institutional, societal and individual levels” (NTWF, 2011: 3). Fay [cited in Reilly, 2005] elaborates on this by noting:

> [Traveller women face] triple discrimination -- as Travellers, as women, and as Traveller women […] Traveller women experience patriarchy in the ways that all women do […] they also experience particular forms of abuse as Traveller women, [particularly] when they are brutalized by descriptions in the media. [para 6]

This intersectional analysis used by Traveller organisations initially sought to highlight the multidimensionality (Crenshaw, 1989: 139) of Traveller women's experience and in doing so acknowledged the intersectional forms of discrimination at micro and structural levels. This also included challenging internal patriarchy and sexism while also contending with external discourses and harmful stereotypes. This framework draws on the work of Kimberlé Crenshaw who coined[116] the concept ‘intersectionality’ in the late 1980s as a critique of the persistent delineation of identity politics and to denote the various ways in which race and gender interact to shape the multiple dimensions of African American women's lives (Crenshaw, 1989: 139). Crenshaw uses the example of anti-discrimination law, where the court would only recognise African American women’s cases on the basis of either gender *or* race, but not both. Crenshaw argues that this mirrors African American women’s experiences within feminist theory and anti-racist politics and discourse, despite experiencing multiple levels of social oppression.

According to Crenshaw, African American women were failed by, (1) anti-racist campaigns that narrowly focused on the experiences and needs of African American men; and (2) feminist campaigns which were primarily led by, and focused on, the experiences of white women. This “single-axis” model (of *either* race *or gender)* of identity failed African American women, as their particular experiences of oppression were rendered invisible by the dominant narrative within the categories “woman” and “Black.” Crenshaw (1989) argues that, “neither Black liberationist politics nor feminist theory can ignore the intersectional experiences of those whom the movements claim as their respective constituents” (166). She argues that such binary practices “relegate the identity of women of colour to a location that resists telling” (Crenshaw, 1991: 1242). The solution, according to Crenshaw, is not to examine racial and gender

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[116] Other African American women scholar-activists such as Audre Lorde (1984) and Angela Davis (1989) had previously rejected the dominant additive model of oppression arguing that African American women’s experience were not simply shaped just by race. They acknowledged that gender, social class, and sexuality were integral to an overall analysis of African American women’s experiences, effectively laying the foundations for Crenshaw (1989) and others (Anzaldúa,1987; Anthias and Yuval-Davis, 1989, 1995, 1996, 2005; Hill-Collins, 1992; 1998; Lughod, 2002; Mahmood, 2005).

oppressions separately and simply stitch them together, but to use an intersectional approach. Using the analogy of a traffic junction, Crenshaw explains (1989: 149):

> Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars travelling from any number of directions and, sometimes, from all of them.

This example of 'flowing' and 'crashing' fosters new ways of understanding how ethnicity and gender intersect in shaping structural, political and representational aspects of women's experiences. Intersectionality has been recognised by human rights monitoring bodies and according to Patricia Schulz, former member of the CEDAW Committee (2013: 6) is defined as:

> … the way to address the compounded discrimination people suffer, based on various grounds, such as race, sex, disability, socio economic status, religion, etc. and to overcome the obstacles of having their rights dealt with in different instruments. The treaty bodies have all recognized this and use the intersectionality analysis in their work. In view of the pervasive nature of discrimination based on sex and gender, the inclusion of sex and gender in the analysis of all the other forms of discrimination is necessary.

The Committee on the Elimination of Racial Discrimination (2000: para 1-2) also recognise the particular experiences of women in relation to racism, noting:

> The Committee notes that racial discrimination does not always affect women and men equally or in the same way. There are circumstances in which racial discrimination only or primarily affects women, or affects women in a different way, or to a different degree than men […] Certain forms of racial discrimination may be directed towards women specifically because of their gender, such as sexual violence committed against women members of particular racial or ethnic groups in detention or during armed conflict; the coerced sterilization of indigenous women; abuse of women workers in the informal sector or domestic workers employed abroad by their employers.

This interrelation dimension, rather than a conflation of identities, is central to understanding how subordination is constructed and institutionalised in practice, thus informing lived experiences. This approach has significantly influenced the work of Traveller and Roma feminists (see e.g., McDonagh, 1994, 2000, 2014; Biţu, 1997; Biţu and Vincze, 2012; Oprea, 2005; 2009; Brooks, 2012, 2015; Kóczé, 2015), as Kóczé (2009: 25) notes:

> Intersectionality and the accompanying notion of multiple discrimination have offered a language for Romani women activists to speak about their experiences with both racism and sexism, of which they have become aware as members of the Roma movement and in their interactions with majority women's movements emerging in different countries.

As Kóczé points out, intersectionality offers a conceptual tool to explicitly name the collective experiences of oppression on the basis of gender and ethnicity. Kóczé also stresses the need to attend to social exclusion and the ways in which sexuality and poverty might intersect with race/ethnicity, gender, and other facets of social identity in Roma women's experiences. This has also been something that has been highlighted by Traveller women. McDonagh (2018) adds to this by reflecting upon the ways in which women also experience ableism and racism on individual and structural levels, arguing, "for those of us who have impairments, and are from Black and Minority Ethnic communities, the impact of implicit and explicit racism has no subtlety" (para 5). Both Kóczé and McDonagh illuminate the ways in which an intersectional analysis pushes the boundaries beyond the conceptualisations of gender and ethnicity and doing so, provides particular insight into the complexities of Traveller and Roma women's experiences. This is something in which Pavee Point and other Traveller organisations have embedded in their work over the years, including a focus on LGBTQI+ Travellers.

Intersectionality as a means of dealing with *multiple* oppressions mutually working together to produce inequalities, has been further developed[117] by feminist scholars[118] including Patricia Hill-Collins (2000, 2002) who offers an alternative perspective by looking specifically at the organisation of intersecting oppressions, through a 'matrix of domination,' for which she describes as:

> The matrix of domination refers to how these intersecting oppressions are actually organized. Regardless of the particular intersections involved, structural, disciplinary, hegemonic, and interpersonal domains of power reappear across quite different forms of oppression. [Hill-Collins, 2002: 18]

Hill-Collins contends with some of the critiques which challenge race as being the most significant marker of group difference. Acknowledging that while class, gender, sexuality, religion, and citizenship status all matter, the historical context of African American's lives (e.g. slavery and segregation) has shaped the ways in which institutionalised racism is felt and lived. For African American women, racism is not an abstract concept that simply "exists in the distance" but as she explains, "we encounter racism in everyday situations in workplaces, stores, schools, housing, and daily social interaction" (Hill-Collins, 2002: 23). This is something that Philomena Essed addresses in her work on 'everyday racism' (1991, 2001). Linking intersectionality to what she calls *gendered racism* positing that, "racisms and genderisms are rooted in specific histories designating separate as well as mutually interwoven formations of race, ethnicity and gender" (Essed, 2001: 1). Essed's work on intersectionality

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[118] See e.g.,Hill-Collins (1998); Lykke (2003, 2005); McCall (2005); Oprea (2005); Verloo (2006); Yuval- Davis (2006) Hankivsky and Cormier (2009)

understands systemic racism as being (re)produced by intertwining systems of domination which are expressed in everyday life, appearing as hidden and normal and thus, requires analyses on both micro and macro levels.

4.8 Structural experiences: social determinants of health

Similar to other migrant, indigenous and minority ethnic groups,[119] contemporary explanations for Traveller women's poor perinatal outcomes and broader health inequalities often narrowly focused on Traveller women's autonomy and individualised health behaviours. This includes Traveller women's higher rates of pregnancy, poor diet, lack of exercise, smoking, lack of engagement in antenatal services/education and lower rates of breastfeeding. This is evidenced in the *Commission on Itinerancy*, the *Review Body Report* and the *All Ireland Traveller Health Study* (AITHS Team, 2010a, 2010b) as discussed in the previous chapters. In addition to a focus on Traveller women's agency and personal responsibility in shaping her health outcomes, 'culture-based frameworks' (Farmer, 2003; 2004) have also been offered as explanations in accounting for such disparities, for example, in relation to marriage practices.

Historically, consanguinity[120] or first-cousin marriage, was a frequent practice particularly amongst elites throughout the United States and Europe (Bittles, 2008; Spencer and Paul, 2008). While there has been a sharp decline in consanguineous marriages since the 19th century,[121] consanguinity has continued to occur globally, with approximately one billion of the current global population living in communities with a preference for consanguineous marriage (Bittles and Black, 2010; Paul and Spencer, 2008; Hamamy, 2012). The highest rates of consanguineous marriage occur in North and sub-Saharan Africa, the Middle East, and West, Central, and South Asia (Bittles and Black, 2010). In North Africa, the Middle East and West Asia, intra-familial marriages account for approximately 20–50% of all marriages (Tadmouri et al. 2009; Bittles 2011; Hamamy et al., 2011, 2012).

Irish Travellers, similar to the majority population, have traditionally practiced both endogamy and consanguinity. While this practice has decreased amongst members of the majority

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[119] See for example: Lara et al. (2005); Escarce et al. (2006); Viruell-Fuentes (2012).

[120] According to Bittles (2001: 90), in clinical genetics, "a consanguineous marriage is most commonly defined as a union between a couple related as second cousins or closer, equivalent to a coefficient of inbreeding in their progeny of $F \geq 0.0156$." This includes unions between first cousins, first cousins once removed and second cousins (Hamamy et al., 2011).

[121] This decline has been attributed to improved transportation and communication, which increased the range of marriage partners; a decline in family size, which limited the number of marriageable cousins; and greater social mobility for women (Spencer and Paul, 2008: 320). For a comprehensive discussion on consanguinity see Bittles (2001, 2008), Spencer and Paul (2008) and Hamamy et al. (2011).

population in Ireland (Barrett, 2016), the trend has appeared to continue among Travellers and other minority ethnic groups.[122] However, aside from anecdotal evidence of consanguineous marriages amongst Travellers, little detailed information is available as data is varied. For example, the *Census of Itinerants* (1960–61) estimated that the vast majority of Traveller marriages were endogamous (89–87%) (TCWG, 2003). The Midlands Traveller cohort study estimated that 83% of Traveller marriages were endogamous, with 72% of marriages consanguineous, and some 40% between first cousins (Flynn, 1986). Yet, the *Congenital Anomaly Study* estimated that almost one in five (19%) Traveller marriages were consanguineous, although this appears to be as a significant underestimate (Barry and Kirke, 1997). TCWG (2003) estimated that approximately 19–40% of all Traveller marriages take place amongst first cousins (TCWG, 2003). However, a more recent estimate by Barrett (2016) suggests that approximately 3,000 or 12% of Traveller marriages were consanguineous. In the absence of disaggregated data on the basis of ethnicity, it is not possible to ascertain an accurate count.

Medical evidence suggests that consanguinity, i.e. first-cousin marriage, can potentially increase the risk of recessive genetic disorders and carries a higher risk of death (TCWG, 2003). Findings from the Bradford/Leeds study[123] (Sheridan et al., 2013, University of Leeds, 2013) confirms that the two main factors associated with an increased risk of babies being born with a birth defect are being born to an older mother or to parents who are blood relations. This is the first study which has explored the potential causes of birth defects[124] in a population where there are enough numbers in both consanguineous and non-consanguineous groups to reach reliable and statistically significant conclusions (Sheridan et al., 2013). According to the research, consanguinity is a risk factor for congenital anomaly, but as Sheridan argues:

> It is important to note that the vast majority of babies born to couples who are blood relatives are absolutely fine, and whilst consanguineous marriage increases the risk of birth defect from 3% to 6%, the absolute risk is still small. [cited in University of Leeds, 2013: para 6)

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[122] According to Barrett (2016), the estimated number of consanguineous couples has grown in subpopulations in Ireland in the past decade, particularly among African and Asian couples: Pakistanis (967 couples), Nigerians (418–794 couples) and d Indians (54–2099 couples).

[123] The authors used questionnaire data from the mothers of children with one or more anomalies from the Born in Bradford study, a prospective birth cohort study of 13, 776 babies and their families in which recruitment was undertaken within a four year period (2007–2011). Details of anomalies were prospectively reported to the study and we cross checked these details against medical records. We linked data for anomalies to maternal questionnaire and clinical data gathered as part of the Born in Bradford study. We calculated univariate and multivariate risk ratios (RRs) with 95% CIs for various maternal risk factors.

[124] According to WHO (2016) birth defects refers to congenital disorders or congenital malformations. Congenital anomalies can be defined as structural or functional anomalies (for example, metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth, or sometimes may only be detected later in infancy, such as hearing defects

Further, the research indicated that this increased risk due to a consanguineous relationship is no greater than that found in pregnancies of white British mothers (over 34 years of age). This supports existing research which suggests that maternal age increases risks for chromosomal abnormalities and congenital malformations (Park et al., 2010; Gill et al., 2012; Frederiksen et al., 2018). Consanguinity is frequently identified by scholars as a key factor in determining Traveller infant health outcomes, specifically as it relates to metabolic or congenital disorders (Barrett, 2016; Lynch et al., 2018). In 1995, the Task Force Report recommended:

> The Department of Health should commission an in-depth analysis by independent experts of issues relating to consanguinity in the Irish context, taking into account the WHO work in the area […] given that Travellers predominantly marry within their own community, marriage of close relatives is common. [Government of Ireland, 1995: 37]

In 2000, the Traveller Consanguinity Working Group (TCWG) was established under the auspices of the Department of Health.[125] In their report, the Working Group dispute two widely held and unsubstantiated beliefs as related to Traveller consanguinity;

1. that Traveller child mortality is significantly due to inherited (metabolic) disorders; and
2. the occurrence of autosomal recessive inherited disorders among Travellers is a direct consequence of cousin marriage.

Instead, the group found that only a small number of inherited disorders[126] were more common amongst Travellers than among the general population and this isn't necessarily a result of consanguinity, as common altered genes can be found in certain populations for a number of reasons[127] (see e.g., Bittles, 1994: 2001). The Working Group (2003: 5-6) made a number of recommendations; this included increasing the provision of information and the potential risks associated with consanguineous relationships in addition to access to non-directive confidential genetic counselling services. It also recommended that health services should be made aware of the report's recommendations and of the best practice guidelines and literature on community genetics approaches to consanguineous marriage (TCWG, 2003: 6). Further, in acknowledging the lack of reliable data in this area, the report recommended that the Department of Health resource the Working Group to develop a comprehensive, multi-disciplinary study of the "impact of consanguineous marriage within the wider context of the history, demography, social structure and religious beliefs of Travellers, and of the Travellers'

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[125] This group was comprised of a range of stakeholders including, independent experts on genomics, Travellers and Traveller organisations.

[126] These include Galactosaemia, Glutaric Acidaemia Type I, Hurler's Syndrome, Fanconi's Anaemia and Type II/III Osteogenesis Imperfecta.

[127] According to the TCWG (2003) the history of the population and forces that have shaped it over thousands of years determine to a large extent the high frequency of disorders and their underlying genetic alterations in the present-day population.

status in Irish society" (5). However, implementation of these recommendations was not prioritised by the Department of Health and the Working Group was disbanded following the publication of the report.

According to the AITHS, the cause of Traveller infant death was limited to a few conditions, notably those related to congenital malformations, metabolic diseases, prematurity and genetic-related diseases. There was one accidental death. With the exception of metabolic diseases, Traveller infants' causes of death are similar to other minority groups, including Australian Aboriginals (Freemantle et al., 2006; Freemantle and McAulley, 2009), New Zealand Maori (Crengle, 2009) and Canadian Indians (Smylie and Adomako, 2009). While socio-economic deprivation has been suggested as the cause of death in these populations (Freemantle et al., 2006) as Harris et al. (2018) point out, socio-economic position is highly patterned by ethnicity, particularly in New Zealand with large inequities between European and non-European ethnic groups (White et al., 2008; Ministry of Health, 2015; Ministry of Social Development, 2016). Therefore careful interpretation must be applied, as ethnic patterning of socio-economic status can be conceptualised as a "marker of institutionalised racism and that experience of racism at the individual level and institutional levels are inter-related" (Harris et al., 2018:16). The authors argue that this analysis warrants further study in longitudinal research, as it can be used to establish a more formally robust mediation analyses.

Furthermore, while consanguinity can, and does, have an impact on some Traveller women's perinatal outcomes, it is not the only factor, as evidenced in the work of Krieger (1993, 2014) and others[128] as will be discussed in Sections 4.12–4.13. Aside from consanguinity, Traveller nomadism has been used as a prominent causal explanation for Traveller infant mortality. This can be traced in early policy documents which focused on Traveller's "primitive and harsh existence" (Government of Ireland, 1963: 103). In both instances, the implication is that Traveller individual action and responsibility matched with State imposed technical solutions (e.g.) standard housing will effectively address Traveller health inequalities. This reductionist approach completely dismisses the extent to which individual actions are embedded in contexts external to individual authority and structured by institutionalised actors, relations, environments and policies (CSDH, 2008). In doing so, it the obscures the impact of multiple

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[128] Jones (1993, 2002); Williams and Collins (1995); Rich-Edwards et al. (2001); Rowley (2001); Mustillo et al. (2005); Williams (2005); Dominguez et al. (2008); Nuru-Jeter et al., 2009; Lu and Halfron (2003); Lu et al., (2010); Rowley and Hogan (2012); Slaughter-Acey et al., (2013); Slaughter-Acey et al., (2016); Truschel and Novoa (2018).

dimensions of social inequality, particularly structural factors in create the necessary conditions for health inequalities to exist. This includes racism, at structural and individual levels which can affect health through a number of pathways (Williams and Mohammed, 2013; Harris et al., 2018). As Schoepf (1993: 59) argues:

> The structure and wider political economy establishes the situation and restricts the options that people can choose as a means of survival. A focus on behaviours tends to obscure the underlying causes of social interaction.

This is reiterated by the Commission on Social Determinants of Health (CSDH) who observe:

> Inequities in health, avoidable health inequalities, arise because of the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, shaped by political, social, and economic forces […] Social injustice is killing people on a grand scale. [2008: ii-1]

Considered as a significant shift in the conceptualisation of health; the CSDH affirm that the unequal distribution of health is not contingent on biological processes but is a result of poor social policies and programmes, unfair economic arrangements and bad politics. It is within this context that the CSDH argues that the structural determinants and conditions of daily life constitute the social determinants of health and are responsible for a major part of health inequalities amongst particular groups. As briefly discussed in Chapter 1, this model has influenced the work of Traveller organisations including PHCTPs. It has also gained considerable popularity among policy makers in Ireland and has been incorporated to an extent, into national health policy frameworks such as *Healthy Ireland: A Framework for Improved Health and Well-being 2013–2025* (Department of Health, 2013).

This approach to health inequalities is reflected in social science scholarship, most notably through a lens of 'social suffering' by medical anthropologists, with some research dedicated specifically to the experience of women (see e.g., Scheper-Hughes, 1992; Finkler, 1994, 2004). However, as Paul Farmer (2004) points out, "because ethnographic work relies on conversations with the living […] we are still not getting the entire picture. An anthropology that tallies the body count must of course look at the dead and those left for dead." (307). It is within this context that Farmer proposes to use the concept of *structural violence* to interrogate the distribution of 'social suffering' by linking the micro and macro level social process that inform, shape, produce and superimpose inequalities on particular bodies.

Structural violence is a conceptual framework to explain the mechanisms through which social forces such as poverty, racism and gender inequality become inscribed on the body resulting in adverse experiences and poor health outcomes (Galtung, 1969, Farmer 1996, 2003, 2004; Farmer et al., 2006). Structural violence refers to institutionalised social structures, such as poverty, racism and gender inequality, that prevent people from meeting their basic needs (Ho, 2007; Shannon et al., 2017). Recognising the multiple and intersecting forms of inequality in the suppression of 'human potential' (Galtung, 1969), structural violence offers a useful lens to consider Traveller women's intersectional experiences of pregnancy loss.

4.9 Structural violence: personal and structural

Structural violence was first coined by Johan Galtung (1969) in seminal work, 'Violence, Peace and Peace Research' where he suggests that there are theoretically significant dimensions of violence which aren't always overt or direct. Rooting his analysis in social injustice, Galtung distinguishes between personal violence (direct violence) with structural violence[129] (indirect violence) to describe the ways in which economic and political structures restrain individuals, groups, and societies from reaching their full potential (Galtung, 1969; Farmer et al., 2006: 1686). According to Galtung, unequal access to resources, political power, education, health care, or to legal standing, are forms of structural violence. Galtung argues that here may not be an individual who directly harms another person in the structure, but rather, the violence is built into the structure, manifesting as unequal power and consequently as unequal life chances. As he notes:

> Structural violence is silent, it does not show - it is essentially static, it is the tranquil waters. In a static society, personal violence will be registered, whereas structural violence may be seen as about as natural as the air around. [Galtung, 1969: 173]

Galtung contextualises this by providing an example of an individual dying from tuberculosis in the eighteenth century, a common death at that time. He argues that this was unavoidable given the lack of medical resources, vaccines, etc. However, he argues that if someone died of tuberculosis today, in light of all of our medical resources then "violence is present" according to his definition (Galtung 1969: 169). The latter infers that the death was avoidable and therefore a result of something much more insidious. Galtung offers another example of life expectancy, and argues that in a society where life expectancy is "twice as high in the upper as in the lower classes, violence is exercised even if there are no concrete actors one can point to directly attacking others, as when one person kills another." (171). This example resonates

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[129] Galtung (1969) makes a clear distinction between *structural violence* and *institutional violence* as he argues it structural is more abstract and not simply contingent on a particular institution. As he explains, "if the police are highly biased the term institutionalized violence may be appropriate, but this is a highly concrete case. There may be violence built into a structure without any police institution at all" (187).

particularly in relation to Travellers' lower expectancy rates, despite clear advancements in medicine and technology.

Galtung's work provided a starting point in re-conceptualising violence as something more than overt physical actions, but as something which can be hidden and covert. In doing so, he argues that structural violence is stitched into the very fabric of social structures manifesting in unequal power and by extension, unequal life chances. This becomes normalised by institutions and everyday experiences, thus remaining invisible, hidden and normal. Galtung (1990) later developed his analysis to include cultural violence, which he defines as *aspects*[130] of culture that can be used to justify or legitimise direct or structural violence (291).

4.10 Structural violence: individual/interpersonal/structural

Building on Galtung, Farmer (2005: 8) uses the concept of structural violence to understand the pathogenic effects of inequality and in doing so, he explicitly links biology with global political economy. Farmer argues that it is in this context that health inequalities are *inscribed* in and on the body through experiences of social inequality, marginalisation and discrimination. It is in this context he frames his analysis of personal experiences within the larger social and economic matrices in which people are located. This framework is useful in considering the ways in which inequality becomes embodied by Travellers, manifesting in higher mortality, shorter life expectancies and chronic diseases (AITHS Team, 2010ab, 2010b).

Farmer argues that structural violence "does not involve bullets, knives, or implements of torture" (Farmer, 2005: 8), but is "structured by historically given (and often economically driven) processes and forces that conspire to constrain agency" (Farmer, 2005: 40). For Farmer, while structural violence can manifest explicitly, it is usually invisible, hidden and embedded in social structures which makes it appear normal and part of the everyday experience. For example, in Ireland, a child born to Traveller parents is three and half times less likely to reach their first birthday, and if the child survives, can expect to live up to 15 years less than a child born to parents in the general population. This child is more likely to develop chronic health conditions such as diabetes, cardiovascular disease and respiratory illness. He/she is more likely to suffer from poor mental health and die by suicide (AITHS Team, 2010a, 2010b).

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[130] Galtung identifies six cultural domains- religion and ideology, language and art, empirical and formal science, which could take the form of "crosses and crescents; flags, anthems and military parades; the ubiquitous portrait of the Leader; inflammatory speeches and posters" (Galtung, 1993: 291). Galtung notes that these are features, or 'aspects of culture,' not entire cultures.

Locating his analysis of structural violence within a health and human rights framework, Farmer argues that structural violence is violence exerted systematically, that is, indirectly by everyone who belongs to a certain social order. In doing so, he links micro-level experiences with the macro structural processes derived primarily from the establishment of neo-liberalism doctrines; he argues that, “human rights abuses are committed in the name of defending and promoting some variant of market ideology” (Farmer, 2005: 6). In further explaining structural violence, Farmer et al. (2006) note that the “arrangements are *structural* because they are embedded in the political and economic organization of our social world; they are *violent* because they cause injury to people” (449). Those with power are not injured, thereby maintaining their position (Farmer et al., 2006: 449). It is within this context that Farmer (1999) contends, that structural violence is not simply by accident “or a *force majeure*”; it is a consequence of “direct or indirect, of human agency” (40). This human agency is implicated through structures that reflect an unequal distribution of power which are historically rooted and economically driven. However, while health inequalities are directly caused by an unequal distribution of resources, this is simply symptomatic of broader issues such as who has the power to decide who those resources are distributed to. Power can enhance the agency of some actors while at the same time, constraining the agency of others. Farmer (2003) explains this is operationalised through routine or the ‘hard surfaces of life,’ which include “racism, sexism, political violence *and* grinding poverty” (43). The tangible outcome of this violence includes death, injury, illness, subjugation, stigmatisation, and even psychological terror (Farmer, 2004: 308).

4.11 Structural violence and intersectionality

Reflecting on previous scholarship, specifically on HIV and AIDS, Farmer argues that the conflation of structural violence and ‘cultural difference’ has dominated much analysis, specifically when it focuses on those “victims of the disease, the poor” (Farmer, 2001: 54). For example, in a review of epidemiological research on the substantive issue, Farmer observes the absence of racism, sexism, and powerlessness; yet at the same time ‘culture’ is an omnipresent sub-theme to the overall narrative. This reflects an exaggeration of agency of those most likely to become infected with HIV, with Farmer suggesting it is tantamount to victim blaming. This parallels with arguments outlined in Section 4.8 as explanations of cultural difference and agency obscure the reality of Traveller health inequalities for what they really are, which, according to Farmer’s definition, is structural violence. Traveller women in this context, as

Farmer suggests, are considered at a higher risk of structural violence based on their social status in Ireland. This includes social factors such as gender, ethnicity and socio-economic status. Sexuality (Goldstein, 2013), gender identity and disability (Muderedzi et al., 2017) have also been identified as social factors in this regard.

Farmer (1996) cautions against simply considering these factors in isolation of one another as they are limited in their explanatory power. Instead, he suggests that we consider the coalescing of various social "axes" to adequately "discern a political economy of brutality" (2003: 43). In effect, what Farmer proposes is an intersectional analysis of structural violence, albeit not using this language. Farmer provides rich ethnographic vignettes of women's stories to illuminate the structural "nature and distribution of extreme suffering" (50). Using the examples of women living with AIDS in three varying contexts (Harlem, USA, Haiti and India), Farmer (2001), argues that in each case, social processes—the economic, political, and cultural forces shape each woman's health outcomes. As he explains:

> Their sickness is a result of structural violence: neither culture nor pure individual will is at fault; rather, historically given (and often economically driven) processes and forces conspire to constrain individual agency. Structural violence is visited upon all those whose social status denies them access to the fruits of scientific and social progress. [Farmer, 2001: 79]

Farmer's overreliance to an extent, on the interaction between gender inequality and poverty misses an opportunity for an in-depth analysis of the ways in which racism also mediates women's experiences in this regard. It is in this context that the concept of structural racism, a dimension of structural violence, is a useful consideration.

4.12 Structural racism

According to Bailey et al. (2017) despite mounting evidence, indicating otherwise, those responsible for defining and responding to public discourse are reluctant to identify racism as a root cause of racial health inequalities. This includes academics, policy makers, scientists, public representatives, journalists, and others (1453). This is caused by a lack of understanding of how a number of factors, including policy and by extension, service provision, act as mechanisms for reinforcing structural racism. However, a number of scholars examining the social determinants of health have identified racism as a mitigating factor in the production of health inequalities (Krieger, 1993, 2014; Williams and Collins, 1995; Jones, 2000, 2002; Rich-Edwards et al., 2001; Rowley, 2001; Rosenburg et al., 2002; Mustillo et al., 2005; Nuru-Jeter et al., 2009; Rowley and Hogan, 2012; Bailey et al., 2017). Within the literature, the concept of structural racism as a conceptual framework has been used to understand the ways in which racism can manifest physiologically and psychologically by becoming inscribed on the bodies of indigenous and minority ethnic groups. According to Bailey et al. (2017: 1453), structural racism refers to:

> The totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice. These patterns and practices in turn reinforce discriminatory beliefs, values, and distribution of resources.

Drawing on structural violence, Bailey et al. (2017) and others argue that structural racism involves interconnected institutions, whose linkages are historically rooted and culturally reinforced. Structural racism refers to the way in which racial discrimination is reinforced through structures and institutions, for example, in accommodation/housing, education, employment, earnings, benefits, credit, media, health care, criminal justice, and so forth (Powell, 2007). These patterns of inequality and racial discrimination in turn reinforce discriminatory beliefs, values, and distribution of resources, which together impact on health outcomes.

A clear example of structural racism is demonstrated in the disparity in perinatal outcomes[131] in the United States. Disaggregating data by ethnicity/race[132] reveals higher rates of maternal and infant death among African American women. For instance, the risk of pregnancy-related deaths for African American women is 3 to 4 times higher than those of non-Hispanic white women (CDC, 2018). In exploring the five medical complications[133] that are common causes of maternal death and injury, Tucker et al. (2007) found that African American women were two to three times more likely to die than non-Hispanic white women who had the same condition. Similar to Travellers, African American women have greater exposure to risk factors during the perinatal period, this includes poverty, low socio-economic status, lack of access to perinatal care, in addition to poor physical and mental health. However, research indicates that these disparities exist even under the most optimal economic conditions for African American women[134] therefore challenging the idea that poverty is the determining factor for such

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[131] For example, African Americans infant mortality rate and sudden infant death syndrome (SIDS) is two times higher than non-Hispanic whites. African American infants are three times as likely to die from complications related to low birth weight as compared to non-Hispanic white infants. In 2014, African American mothers were two times more likely than non-Hispanic white mothers to receive late or no prenatal care (CDC, 2017; United States Department of Health and Human Services Office of Minority Health, 2018;).

[132] The U.S. Center for Disease Control and Prevention (CDC) includes both racial and ethnic categories in accordance with guidelines provided by the U.S. Census Bureau. Racial categories, "reflect a social definition of race […] and not an attempt to define race biologically, anthropologically, or genetically" (U.S. Census Bureau, 2013: para 2).

[133] National data sets were reviewed to calculate prevalence and case-fatality rates among black and white women for pre-eclampsia, eclampsia, abruptio placentae, placenta previa, and postpartum haemorrhage (Tucker et al., 2007).

[134] This is generally measured by income and education

disparities (Mustillo et al., 2005; Dominguez et al., 2008; Slaughter-Acey et al., 2013; New York City Department of Health and Mental Hygiene 2016; Slaughter-Acey et al., 2016).

One of the first studies examining the biological consequences of racism on birth outcomes was reported in 2000 (Collins et al., 2000), and was followed by other studies[135] which argues that American women's experiences of racism on individual, interpersonal and institutional levels are strong predictors of adverse birth outcomes. This has been acknowledged by health providers in the U.S., including the American College of Obstetricians and Gynaecologists (2015: 4) who have committed to eliminating racial and ethnic disparities and note:

> Addressing social determinants of health is critical to reducing inequities in health status. Studies suggest that race and language concordance between patients and practitioners may improve communication and outcomes […] obstetrician–gynaecologists and other health care providers must acknowledge the role they play in perpetuating health care disparities and must advocate for a system of more culturally and linguistically appropriate care for all.

Further, American Indians and Alaska Native women experience similar perinatal outcomes to their African American counterparts and share a historical experience of institutional racism. Where data exists, American Indian and Alaska Native women are 4.5 times more likely to die from pregnancy and childbirth related causes than non-Hispanic white women. Similar to Travellers, in terms of perinatal mortality, American Indian and Alaska Native infants are nearly twice as likely to die by their first birthday as non-Hispanic white infants, with the most common causes being congenital malformations, sudden infant death syndrome (SIDS), and prematurity. The infant mortality rate remains persistently high[136] amongst American Indian and Alaska Natives, as they are the only racial/ethnic group in the United States that did not experience a decline in infant mortality in the period between 2005 and 2014 (CDC, 2017). However, as Truschel and Novoa (2018) suggests, given data challenges[137] and in the absence of robust disaggregated data on the basis of ethnicity, current statistics are possibly an undercount:

> The racial disparity in maternal and infant mortality between American Indian and non-Hispanic white communities is a problem that has only grown in recent years. Data challenges related to racial misclassification suggest that the problem is sadly even more grave than it appears. [para 17]

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[135] According to Rosenberg et al. (2002); Dole et al. (2004); Rankin et al., (2011); Slaughter-Acey et al. (2016); racism increases African American women's risk of pre-term birth, with excess risk ranging from 1.3 to 3 fold.

[136] The infant mortality rate for American Indian and Alaska Natives is almost twice the rate of the non-Hispanic white infant mortality rate (CDC, 2017).

[137] Similar to Travellers, American Indians and Alaska Natives are a small minority ethnic group in the United States, comprising of approximately 2% of population. As a result, American Indians and Alaska Natives are often overlooked in public health research for two reasons. First, because of their small sample size in statistical terms, American Indians are often dropped from national reports and/or not included in analyses. Second, the use of proxy based data which can lead to ethnicity/race misclassification.

This is in the broader context of Native American and Alaskan Native experiences of racism and discrimination in health settings, with one-quarter of Native Americans reporting experiences of racial discrimination when accessing health services in the United States (Harvard T.H. Chan School of Public Health et al., 2017:8). Additionally, over one in ten Native Americans respondents (15%) reported avoiding accessing health services for themselves or a family member due to concerns of poor treatment or discrimination based on their ethnicity (Harvard T.H. Chan School of Public Health et al., 2017: 12). These statistics cannot be decoupled with American Indian and Alaska Native women's lack of/delayed access to antenatal care; where they are 2.5 times more likely to receive late or no antenatal care when compared to non-Hispanic white women (U.S. Department of Health and Human Services Office of Minority Health, 2018).

4.13 Locating structural violence in the perinatal period: obstetric violence

In the past three decades, NGOs and international human rights globally have called attention to the widespread mistreatment and abuse of women's bodies during the perinatal period[138] (Bellón Sánchez, 2014; Chadwick, 2017b, 2018; Manning and Schaaf, 2018; Schwartz, 2018). Present in academic and activist scholarship since the 1950s (Rich, 1986; Martin, 2001a; Kitzinger, 2006; Richland, 2008; Goer, 2010), the types of violations discussed in the preceding sections have recently been acknowledged as a global health and a human rights issue (d'Oliveira et al., 2002; Small et al., 2002; White Ribbon Alliance, 2011; Silal et al., 2012; WHO, 2014; Bellón Sánchez, 2014; Abuya et al., 2015; Sadler et al., 2016; Shabot, 2016). Following an intensive campaign by women's groups, feminists, NGOs and range of other stakeholders[139] in highlighting the global and systemic nature in which women experience disrespect and abuse during labour and childbirth, the World Health Organization (WHO) explicitly acknowledged this as a key threat to public health. In doing so, it called for greater action, dialogue, research and advocacy noting:

> Every woman has the right to the highest attainable standard of health, which includes the right to dignified, respectful health care […] Many women experience disrespectful and abusive treatment during childbirth in facilities worldwide. Such treatment not only violates the rights of women to respectful care, but can also threaten their rights to life, health, bodily integrity, and freedom from discrimination [WHO, 2014: 1]

Rooting their analysis within a human rights framework, WHO argues that every woman has the right to the highest attainable standard of health, which includes the right to dignified,

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[138] See submissions to UN Committee on Torture (2018)

[139] For example, international and regional bodies, public health agents and researchers

respectful health care throughout pregnancy and childbirth, in addition to the right to be free from violence and discrimination. Abuse, neglect or disrespect right across the perinatal period constitutes a clear violation of women's rights and fundamental freedoms as set out in core international human rights treaties[140] and internationally adopted human rights standards and principles.[141] However, in the absence of an international consensus on how disrespect and abuse should be defined and/or measured, despite existing evidence indicating the global scale in which women experience disrespect, it is difficult to quantify the extent to which it exists and where, in addition to its impact on women's health and well-being. Consequently, WHO has called for a robust research agenda to "better define, measure and understand disrespectful and abusive treatment of women during childbirth, and how it can be prevented and eliminated" (WHO, 2014: 2). The statement was endorsed by more than 90 international, civil society, and health professional organisations (Khosla et al., 2016) and further highlighted in 2015 in a joint statement by a number of UN human rights experts, including the UN Rapporteur on the Rights of Women of the Inter-American Commission on Human Rights and the Special Rapporteurs on the Rights of Women and Human Rights Defenders of the African Commission on Human and Peoples' Rights, as they urged States to:

> Address acts of obstetric and institutional violence suffered by women in health care facilities, including with respect to forced or coerced sterilization [sic] procedures, refusal to administer pain relief disrespect and abuse of women seeking health care and reported cases of women being hit whilst giving birth. [Rapporteur on the Rights of Women of the Inter-American Commission on Human Rights et al., 2015: para 8]

In 2017, WHO released another statement and in acknowledging the global scale of obstetric violence, it argues:

> Mistreatment of women during childbirth a sad reality worldwide […] mistreatment of women during childbirth occurs in countries across the world and puts the lives and well-being of women at risk. It also constitutes a violation of the right to the highest attainable standard of health, which includes the right to dignified, respectful health care throughout pregnancy and childbirth, as well as the right to be free from violence and discrimination. [para 1-8]

Several studies including Bohren et al. (2015), Diniz et al. (2015), Molina et al. (2016) Balde et al. (2017) have highlighted different types of obstetric violence prevalent across the globe. In their landscape analysis of abusive maternal care, Bowser and Hill (2010) describe seven categories of disrespectful and abusive care during childbirth:

1. Physical abuse
2. Non-consent to medical care

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[140] Such as the Universal Declaration of Human Rights (UDHR), The UN Declaration on the Elimination of Violence against Women (CEDAW) and the UN International Covenant on Economic, Social and Cultural Rights (CESCR, 2016)

[141] This includes the right to be equal in dignity, to be free to seek, receive and impart information, to be free from discrimination, and to enjoy the highest attainable standard of physical and mental health, including sexual and reproductive health.

3. Non-confidential care
4. Non-dignified care
5. Discrimination[142]
6. Abandonment
7. Detention in health facilities

Drawing on this landscape analysis, Balde et al. (2017), in their multi-country study[143] on the mistreatment of women during childbirth, reported that mistreatment exists in Guinea and occurs in many forms, including physical and verbal abuse, neglect and abandonment. In the study, participants described being slapped by providers, scolded for non-compliance with practitioners' requests, giving birth on the floor and without a medical professional in the health facility (3). The authors also asked all participants (i.e. women, providers, administrators) what factors they perceived to influence mistreatment during childbirth. These factors are related to four main categories: (a) essential physical resources; (b) health system and work force; (c) service providers' attitudes and practices; and (d) women's characteristics and behaviour (3). Further, in research conducted by Hameed and Avan (2018) in Pakistan[144], approximately 97% of women reported experiencing at least one disrespectful and abusive behaviour. Experiences of mistreatment by type were as follows: non-consented care (81%); right to information (72%); non-confidential care (69%); verbal abuse (35%); abandonment of care (32%); discriminatory care (15%); and physical abuse (15%). Da Silva et al. (2014) adds to this by identifying three different types of obstetric violence which emerged in their fieldwork in Brazil: (1) violent and aggressive speech by doctors, nurses and other health personnel (2) unnecessary/negligent medical procedures ('iatrogenic' procedures); (3) and institutional unpreparedness such as inadequate physical facilities, equipment, ambience and management. The latter includes non-compliance with obstetric protocols for the humanisation of assistance during pregnancy.

Drawing on existing literature, and in an attempt to define precisely what is considered as 'abusive or disrespectful' particularly at individual, structural and policy levels, Freedman et al., (2014) propose that disrespectful and abusive care during childbirth are the, "interactions or facility conditions that local consensus deem to be humiliating or undignified, and those interactions or conditions that are experienced as or intended to be humiliating or undignified"

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[142] This includes: HIV status, ethnicity, age, marital status, language, economic status, educational level, etc.

[143] This study draws on an existing research project by Vogel et al. (2015). Country sites include: Guinea, Ghana, Nigeria and Myanmar.

[144] This research was based on a large population-based, cross-sectional survey conducted across 14 districts in Sindh Province (Jamshoro, Matiari, Ghotki, Shikarpur, Jacobabad, Khairpur, Qambar Shahdadkot, Larkana, Tando Alayar, Naushero Feroze, Karachi) and Punjab Province (Dera Ghazi Khan, Rahim Yar Khan, Rajanpur) in Pakistan. 1,334 interviews were conducted with women aged 15–49 who had had a live birth over the past 12 months (Hameed and Avan, 2018).

(917). Rooting their analysis within a broad human rights framework, specifically the right to dignified, respectful sexual and reproductive health care,[145] they suggest that mistreatment during childbirth can represent a violation of women's fundamental human rights. Freedman and Kruk (2014) note that abuse is not simply isolated to individual cases, but also occurs on structural and policy levels (see Figure 1). Bohren et al. (2015) add to this by suggesting that[146] the mistreatment of women during childbirth occurs on both micro and macro levels, in interactions between the woman and provider, as well as through systemic failures at the health facility and health system levels (1). The authors identify a 'typology' of violence which includes: physical abuse, sexual abuse, verbal abuse, stigma and discrimination, failure to meet professional standards of care, poor rapport between women and providers, and health system conditions and constraints.

Given the clear parallels between the mistreatment of women in obstetric settings and violence against women (more broadly), Jewkes and Penn-Kekana (2015) propose to radically redefine this issue as 'obstetric violence.' The intentional use of the term *violence* in this context instead of more neutralised language such as 'mistreatment' is rooted in an effort to problematize practices, which have often been hidden, invisible and unacknowledged. It is also an effort to politicise women's experiences and reframe them within a broader field of structural inequalities and violence against women (Figure 2) (Bellón Sánchez, 2014; Smith-Oka, 2015; Zacher Dixon, 2015; Chadwick, 2018; Betron et al., 2018). Recognised distinct from other forms of overt medical violence, for example, as those documented in the Doctor's Trial of Nazi physicians at Nuremberg in 1946-4, obstetric violence is, "overtly political and provocative" (Chadwick, 2018: 102) and used to challenge abusive practices which have been normalised both socially and culturally. Promoted by women and civil society groups across borders, "the very pairing of the terms obstetric and violence is unexpected, jarring, and provocative" (Zacher Dixon, 2015: 450) as it is directly linked to efforts to critique social relations or marginalisation, embedded in class, gender and ethnic oppressions (Smith-Oka, 2015; Zacher Dixon, 2015; Chadwick, 2018). Obstetric violence, Sadler et al. (2016: 50) argues can be understood as a consequence of structural violence, that is, as invisible manifestations of violence that are built into the fabric of society, producing and reproducing social inequalities across groups (Galtung, 1969; Farmer, 2004; Montesanti and Thurston, 2015).

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[145] As in the *Universal Rights of Childbearing Women Charter* (White Ribbon Alliance, 2017).

[146] This article is based on a systematic review conducted across all geographical and income-level settings

However, as Khosla et al. (2016), Sadler et al. (2016), Chadwick (2018) and others[147] point out, explicit use of obstetric violence can be used as a tool to potentially reframe the international agenda on disrespect and abuse as set by WHO (2014) and to contribute to positive change in maternity services globally.

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[147] See e.g.,da Silva et al. (2014, 2016); Diniz et al. (2015); Smith-Oka (2015); Zacher Dixon (2015); Diaz-Tello (2016); Shabot (2016); de Oliveira (2017).

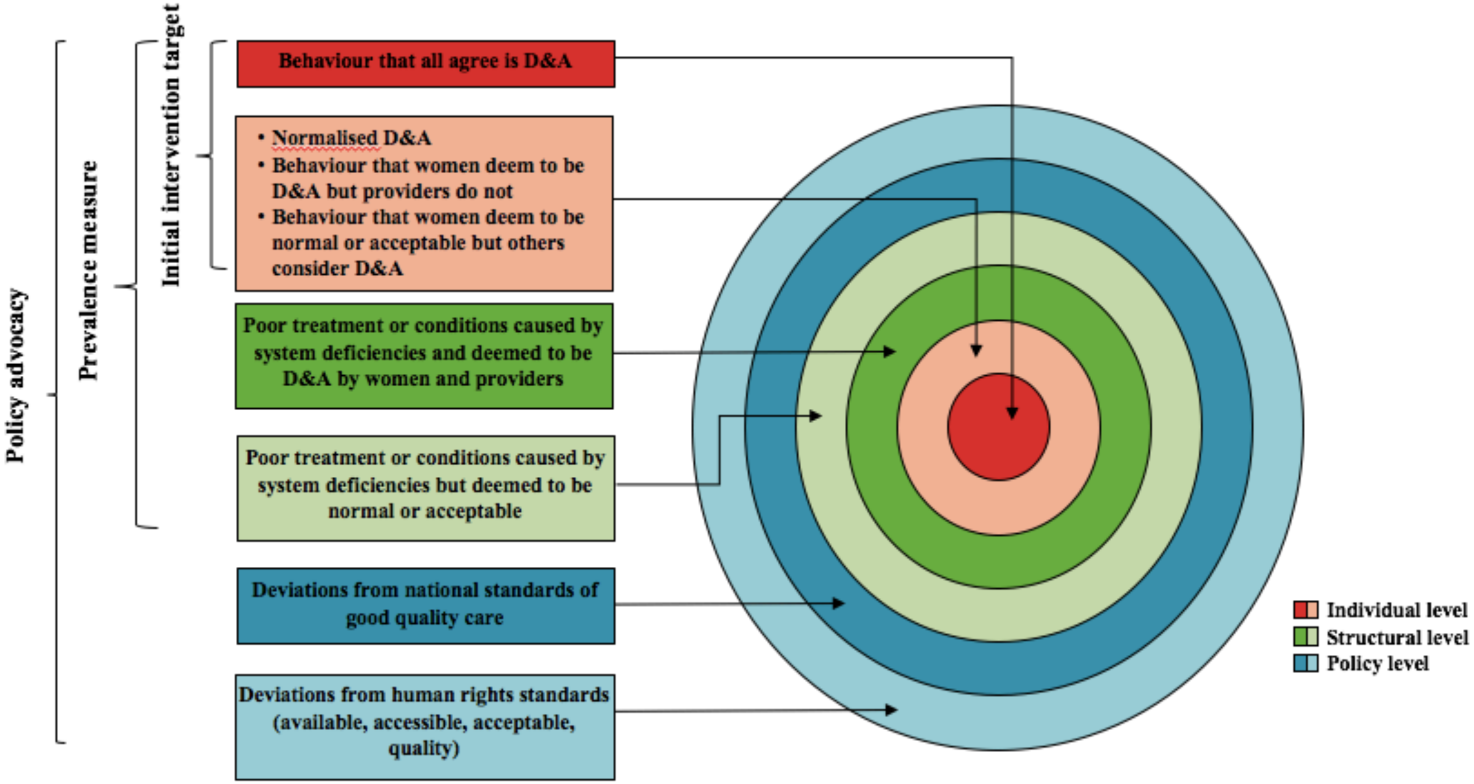

Figure 1: Defining disrespect and abuse (D&A) of women in childbirth (Freedman and Kruk, 2014)

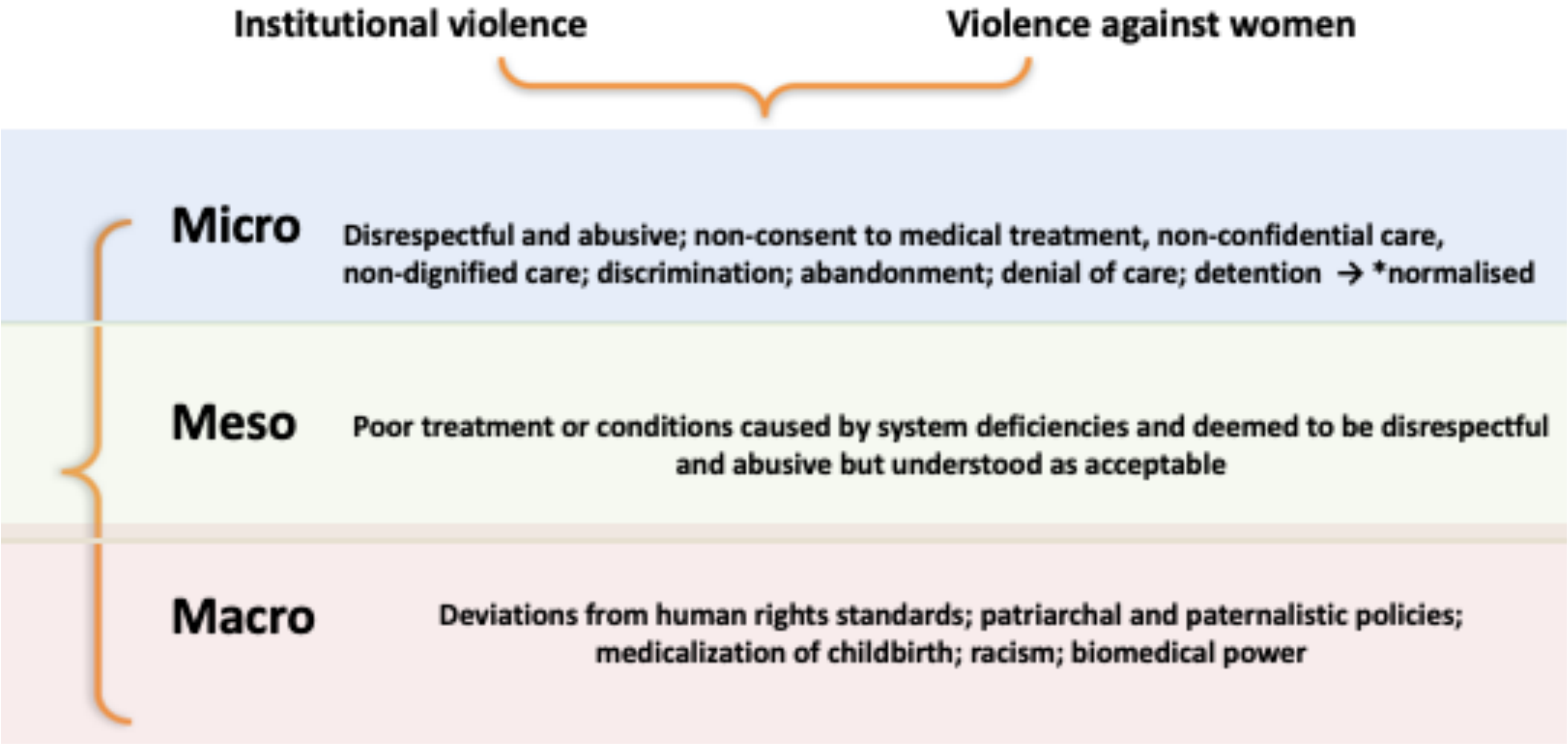

Figure 2: Defining obstetric violence (micro, meso and macro levels)

While only recently gaining popularity amongst scholars in this area, reference to obstetric violence is evident in medical documents since 1827 when Dr. James Lundell (1827) referred to umbilical cord tearing during a lecture on the theory and practice of midwifery:

> Floodings, tremendous lacerations, inversions of the uterus, like those which now stand on the table before you, such are the effects of obstetric violence, ferocious and atrocious obstetric violence; that insatiate and gory Moloch, before whose bloody shrine so many thousands have been sacrificed, to be succeeded, in future years, by still more numerous victims. [Lundell, 1827: 45]

Blundell, in subsequent lectures cautioned his colleagues against obstetric violence, whether through "instruments or the hands," (Blundell, 1842: 354-6), noting that violence has no place in midwifery (237). The concept has since evolved from Blundell's initial lectures, with definitions developed in legislation and in academic scholarship. For instance, in 2004 Argentina passed a law for humanised birth that put forward the rights of every pregnant woman to information as well as to dignified, respectful, and high-quality maternity care (Government of Argentina, 2004: para 1). This was followed by Venezuela in 2009 (Pérez-D'Gregorio, 2010) as they became the first country to formally criminalise and define obstetric violence as the:

> Appropriation of women's body and reproductive processes by health personnel, which is expressed by a dehumanising treatment, an abuse of medicalisation and pathologisation of natural processes, resulting in a loss of autonomy and ability to decide freely about their bodies and sexuality, negatively impacting their quality of life. (Translation by Sadler et al., 2016: 4)

Following Venezuela, some states in Mexico have included obstetric violence within the legislation on gender inequalities and violence. While civil society groups have welcomed the development of effective mechanisms to secure accountability for women, they also caution against reducing cases to merely isolated incidences of interpersonal relations between individuals and health professionals (Williams et al., 2018). Doing so, they argue, masks the very structural inequalities that create the conditions for violence to occur. Without a structural analysis, States effectively obscure their own failures and avoid accountability (Pickles, 2017). This definition indicates the gendered and structural nature of violence, thus requiring a systemic response.

4.14 Hidden forms of violence: meso/macro

Each of these particular examples presents clear cases of *direct physical acts* that can be seen as tangible forms of violence. However, as discussed above, obstetric violence must be understood as deeply embedded in social norms and material relations of domination and power, that is, multiple, shifting, relational, emergent and entangled with a range of socio-material forces, discourses, objects, norms and structures" (Chadwick, 2018: 104). It is in this context that we need to look 'sideways' (Žižek, 2008) at the contextual factors that allow violence to materialise as hidden, invisible and normalised. For Žižek (2008: 1), it is a mistake to simply attend to *subjective violence*, that is direct violence or "obvious signals of violence […] and acts of crime violence" enacted clearly by an identifiable agent or evil individuals at the expense of failing to critically assess *objective violence*, that is, violence inherent to the 'normal' state of things. Objective violence in this context is invisible since it, "sustains the very zero-level standard against which we perceive something as subjectively violent" (1). Such hidden or subtle forms of violence create the necessary conditions for objective violence to occur and to become normalised. According to Žižek, we must cast the analysis sideways and "perceive the contours of the background which generates such outbursts" (1). A number of terms have been used to describe these subtle forms of violence including, 'soft' (Colaguori, 2010), structural (Galtung, 1969; Farmer, 2004), symbolic (Bourdieu, 1989) and objective violence (Žižek, 2008). Such hidden forms of violence are shaped by competing priorities, intra-acting forces, structures and socio-material relations which become internalised and deeply entrenched in normative power relations and discourse.

Exerted systematically, this type of violence is central to reproducing structures of hegemony and control, or as Farmer (2004) argues, it is intended "to inform the study of the social machinery of oppression" (307). This has corporeal consequences, particularly on women, as the rights of women are violated in innumerable ways which becomes regulated and inscribed on women's bodies as outlined in the work of Farmer (2004). In Ireland, this is evidenced in the State's preoccupation of ensuring control of women, particularly in relation to sexuality and reproduction. Travellers were not immune to this as outlined in Chapter 2. However, the State's approach to Traveller women in this regard has differed and has been pronounced by assimilation and institutional racism (McDonagh, 2000, 2014; Pavee Point and NTWF, 2017). In examining these hidden forms of violence, scholars have focused on the consolidation of biomedical hegemony through the use of obstetric power, resulting in the production of women's bodies as submissive, passive, docile and compliant in obstetric settings (Davis, 1988; Davis-Floyd and Sargent, 1992; Ginsburg and Rapp 1995, 1999; Denny, 1996; Jordan, 1997; Davis-Floyd and Dumit 1998; Martin, 2001a, 2001b; Rapp, 2004; Lorentzen, 2008; Chadwick et al., 2014). According to Chadwick (2018), "silence matters and tells us something about the ontological politics of birth" (1). When such experiences become normalised, they become less problematised or theorised and these assumptions about the nature of women's bodies pervade medical practice.

4.15 Obstetric violence and intersectionality

Given that scholarship in this area is emerging, there are a limited number of scholars using obstetric violence as a conceptual tool to describe violence against women in obstetric settings. In an Irish context, no study to date has adopted the term explicitly to explore women's experiences of pregnancy, labour, childbirth or loss. While the concept of obstetric violence assumes an intersectional approach, with biomedicine understood as intertwining with ethnicity, class and gendered modes of marginalisation. Yet, there has been very little scholarly attention in this regard,[148] despite the historical global context in which indigenous and minority ethnic women's bodies have been the terrain in which the majority population has assumed domination and control through abusive and violent practices (Roberts, 1999; Castro et al., 2015).

The increased risk of human rights violations in the context of reproductive health care, based on sex and/or gender and other intersecting factors[149] has been well documented[150] and is often framed within an intersectional analysis as discussed in Chapter 4, Section 4.7 (Khosla et al., 2016). A number of UN treaty-monitoring bodies[151] have highlighted the increased risk of the denials of reproductive health services and information to girls on the basis of age, and disability (OHCHR, 2016). The CEDAW Committee have linked poor quality of care in the case on maternal mortality to the intersecting factors such as gender, race, and socio-economic status.[152] This has been supported by the former Special Rapporteur on the Right to Health, Paul Hunt, who argues (2006), "marginalised women, such as women living in poverty and ethnic minority and indigenous women, are more vulnerable to maternal mortality (6).

Marginalised women, specifically poor women, indigenous women and women from minority ethnic groups have a long history of systematic mistreatment and abuse in obstetric settings, including forced and coerced sterilisation in order to control their 'unhealthy birth rate'

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[148] See e.g.,Chadwick (2018)

[149] This includes age, race/ethnicity, socio-economic, migration, and/or health status, sexual orientation/gender expression, disability, and/or location.

[150] See Khosla et al. (2016) for a comprehensive discussion

[151] For example, the HRC, the UN Committee on the Rights of the Child (CRC), the UN Committee on the Elimination of Discrimination against Women (CEDAW) and the Committee on the Rights of Persons with Disabilities (CRPD) (OHCHR, 2016).

[152] See the Committee's consideration of the case of Alyne da Sliva Pimentel v. Federative Republic of Brazil (CEDAW, 2011).

(Hernandez, 1976; Espino, 2000; Lawrence, 2000; Vicenti-Carpio, 2004; Holt, 2005; Curran, 2011; 2016). Feminist scholarship has documented the extent to which women's bodies have been used as laboratory subjects, akin to that of animals, manipulated and experimented on without their consent. This was often in the context of testing obstetric procedures before they could be made available to women in majority populations (Hill-Collins, 1994; Roberts, 1999; Davis, 2003; Washington, 2006; Chinyere-Oparah et al., 2015). This is clearly evidenced in the horrific violence, or 'medical apartheid' that was inflicted upon enslaved African American women's bodies in the United States in the name of obstetrics and gynaecology (Washington, 2006; Chinyere-Oparah et al., 2015). This was most notably demonstrated by Dr. Marion Sims[153] perfecting his surgical skills on African American women, Sims purchased enslaved women for the sole purpose of conducting experimental operations (Washington, 2005, 2006; Chinyere-Oparah et al., 2015). Sims was a celebrated medical figure; in 1876 he became president of the American Medical Association (AMA) and later founded the American Society of Gynaecology (Wailoo, 2018). A number of commemorative statues of Sims were erected throughout the United States, most notably in Central Park, New York. However this statute was removed in 2018 following a concerted effort by historians, scholars, and activists who urged the city council to remove[154] it (Savej, 2018; Nadja, 2018; Waxman, 2018; Zhang, 2018). According to activist Marina Ortiz (2018):

> Throughout our campaign, we maintained that the statue's presence did a huge disservice to the neighborhood's [sic] majority Black and Latino residents, groups that have historically been subjected to medical experiments without permission or regard for their well-being. Dr Sims is not our hero, and we don't need any reminders of his barbarities. [cited in Sayej, 2018: para 10]

Similarly, across the United States minority ethnic women, including African American, Puerto Rican, Chicana and indigenous American Indian women were systematically targeted for forced and coerced sterilisation in the 20th century (Hernandez, 1976; Espino, 2000). While these procedures were largely performed under the auspices of eugenic laws in the U.S.,[155] women bodies were also used as live cadavers in teaching hospitals for medical residents to practice their technique (Hartmann, 1995; Roberts, 1999). While not official policy, the performance of elective hysterectomies on poor women and women from minority ethnic groups have been cited as opportunities to train medical students (Hernandez, 1976; Hartman, 1995; Kapsalis, 1997; Wallace-Sanders, 2005). In the early 1970s, in an interview with Biloxi

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[153] Sims is often regarded as the "Father of Modern Gynaecology" and the "Architect of the Vagina" ((Waxman, 2018; Savej, 2018; Zhang, 2018).

[154] This included protests and a submission of a petition with 26,000 signatures in support of removing the statue.

[155] See the U.S. Supreme court case of *Buck vs. Bell* (1927) which validated a Virginia law that mandated sterilisation for people who had been declared as "socially inadequate" (Lombardo, 2008; Nsiah-Jefferson, 1989; Haller, 1984 [1963]). This was interpreted widely and disproprtionately targeted poor women, women with disabilities and minority ethnic women (Roy et al, 2012; Lombardo, 2008)

Daily Herald Newspaper, Acting Director of Obstetrics and Gynaecology at New York City municipal hospital explained:

> In most major teaching hospitals in New York City, it is unwritten policy to do elective hysterectomies on poor Black and Puerto Rican women, with minimal indications, to train residents, explained the director of obstetrics and gynaecology at a New York municipal hospital. At least 10% of gynaecological surgery in New York City is done on this basis. And 99 percent of this is done on Black and Puerto Rican women [Payne, 1974:8]

Research conducted by Pinkerton-Uri (as cited in Lawrence, 2000) estimates that 25,000 American Indian women between the ages of 15 and 54 were subject to forced or coerced sterilisation up until the 1970s. In most cases, women were presented with consent forms whilst heavily sedated during C-sections or active labour. However, as Pinkerton-Uri indicates, most women could not understand the written consent forms given their poor literacy. Further, Pinkerton-Uri notes that in instances where women refused consent to such procedures, they were met with the threat of losing their children and/or their social protection payments. Other scholars have documented cases of American Indian girls as young as eleven having received forced or coerced hysterectomies (Vicenti-Carpio, 2004). A 1976 report by the U.S. General Accounting Office reviewed the medical files of American Indian women between 1973 and 1976 and found that 3,406 women were sterilised without their permission by federally funded Indian Health Services.[156] However, Women of All Red Nations, an indigenous women's organisation, argues that this is an undercount, with sterilisation rates as high as 80% on some reservations (cited in Lawrence, 2000; Ralston-Lewis, 2005; Smith, 2005).

Comparably in Europe, Roma women have historically been targeted for State sanctioned eugenic programs; this includes under the Nazi regime and thereafter.[157] In the former Czechoslovakia, for instance, between 1970 and 1990 tens of thousands of Roma women were coercively sterilised to prevent the 'social risk' that Roma were deemed to pose by reducing what was conceptualised as an 'unhealthy' birth rate (ERRC, 2004, 2006, 2010). Such practices did not simply dissipate, with Roma women's coercive sterilisation cases documented as recently as 2007. This has been highlighted by numerous human rights bodies and UN treaty-monitoring bodies including the Committee on the Elimination of Discrimination against

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[156] According to United States General Accounting Office (1976), consent forms varied in each jurisdiction, however, the most widely consent form used by IHS did not (1) indicate that the basic elements of informed consent had been presented orally to the patient, (2) contain written summaries of the oral presentation, and (3) contain a statement at the top of the form notifying subjects of their right to withdraw con- sent. One consent form document did meet the Indian Health Service requirements, but when used was filled out incorrectly. This occurred in 4 of the 12 (30%) Indian Health Services.

[157] For example, in 1978 in the former Czechoslovakia, Romani women were routinely sterilised without their consent as a matter of government policy (European Roma Rights Centre, 2010)

Women (CEDAW) (Holt, 2005; ERRC, 2010; Zampas and Lamačková, 2011; Curran, 2016; Center for Reproductive Rights, 2017). However, similar to Pinkerton-Uri's research (as cited in Lawrence, 2000) in many documented coercive sterilisation cases of Roma women, written consent forms were presented to Roma women under duress, particularly during C-sections or active labour (Khosla et al., 2016). For example, in a case involving the coercive sterilisation of a Roma woman during an emergency Caesarean section[158] the CEDAW Committee (2006) found that the sterilisation was performed on the woman "without her full and informed consent (17). Referring to the woman's medical records, the Committee noted that the woman was in a very poor state of health when she was informed about the procedure and her consent obtained. Before leaving the hospital, the woman asked the doctor for information on her state of health and when she could try to have another baby. It was only then that she learned the meaning of the word "sterilisation" (3). In its decision, the Committee (2006) argued that there were serious violations to the woman's human rights, with the State party permanently depriving the woman of her natural reproductive capacity. As the Committee notes:

> The woman did not understand the Latin term for sterilization [rather than the Hungarian word for sterilization] that was used on the barely legible consent note that had been handwritten by the doctor … [She was not given] information in a way in which she was able to understand it […] The Committee further stated that States parties should not permit forms of coercion, such as non-consensual sterilization ... that violate women's rights to informed consent and dignity. The Committee considers in the present case that the State party has not ensured that the author gave her fully informed consent to be sterilized and that consequently the rights of the author under article 12 were violated [CEDAW, 2006: 16-17]

Furthermore, contemporary research has documented Roma women's experiences of racism, discrimination and abuse in obstetric settings (Janevic et al., 2011; Colombini et al., 2012; Janevic et al., 2017; Watson and Downe, 2017). Roma women throughout Europe report physical and psychological abuse, discrimination, neglect and abandonment, segregation, isolation and detention in maternity hospitals following childbirth because of their inability to pay (Khosla et al., 2016). While there is a paucity of comparable research in Ireland,[159] Roma women, similar to Traveller women, experience a high level of racism and sexism. Roma women in particular report experiencing racism and verbal abuse in public spaces and are subjected to racist comments by service providers (Pohjolainen, 2014; Pavee Point and DJE, 2018). Racism is explicitly and openly articulated by senior public officials, including elected representatives and members of the judiciary, which becomes reinforced in public discourse

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[158] See the Committee's decision in the case of Ms. A. S. vs. Hungary (CEDAW, 2006).

[159] While *Roma In Ireland: A National Roma Needs Assessment* (Pavee Point and DJE, 2018) includes findings in relation to maternal and child health it does not provide a qualitative analysis on Roma women's experiences with maternity care. The report did identify maternal health as a key concern with almost 1 in 4 Roma women (24%) reporting that they had not accessed health services while pregnant and their first point of access was to give birth.

and attitudes towards Roma. This is reflected in the most recent ERSI and Irish Human Rights and Equality Commission's report (McGinnity et al., 2018) which found that the majority (75%) of the Irish population would not allow Roma (some or many) to come to Ireland.[160] Roma in Ireland report experiencing racism at both institutional and individual levels, with 81.1% of Roma participants in the National Roma Needs assessment reporting experiences of racism and verbal abuse in public spaces, with Roma women identified as particularly vulnerable to racist abuse (Pavee Point and DJE, 2018).

Pohjolainen (2014) describes Roma women's experiences in Ireland, which includes experiences of overt and/or covert racism, prejudice and inappropriate treatment by health care practitioners (88). Negative and differential treatment is especially reported in cases where Roma women have insufficient or no English or with whose appearance is more objectively 'traditional" (e.g.) clothing, physical appearance, etc. Framing such experiences within a structural analysis, Pohjolainen (2014) argues that while many health professionals in Ireland work in a positive and informed way with Roma women, practices reported by Roma women by other health professionals reflects evidence of institutional racism in attitudes, behaviours and processes. These can be based on unconscious ignorance, prejudice, negligence and racist stereotyping, which have led to the disadvantage of Roma women (88). Such experiences build on a legacy of negative past experiences for Roma women who may have come from countries where maternity services are defined largely by racist treatment, segregation, outright denial of services and refusal of services due to socio-economic status (lack of ability to pay). This can have a negative impact on Roma women's engagement with maternity services as identified in the National Roma Needs Assessment, which reported that one in five Roma women did not access antenatal care prior giving birth in Ireland (Pavee Point and DJE, 2018: 100).

4.16 Conclusion

This chapter has provided an empirical and theoretical framework to contextualise this study, responding to its overarching aims and objectives. As such, it presented a critical review of relevant research available on pregnancy loss, paying particular attention to the personal, interpersonal and structural dimensions of loss. This chapter also introduced key concepts that derived from women's narratives during data collection and after extensive analysis in line

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[160] According to McGinnity et al. (2018) only 25% of respondents would allow *many or some* more Roma to come to Ireland

with emergent findings; including intersectionality, structural violence, structural racism, gendered racism and obstetric violence. The next chapter presents the philosophical and theoretical underpinnings of this study. It provides an overview of the research paradigm, theoretical framework, addressing both the ontological and epistemological positioning of the study. It also discusses the recruitment and key methods used for data collection and analysis.

Chapter 5

Methodology

5.1 Introduction

This chapter presents the philosophical and theoretical underpinnings of this research. It provides a detailed discussion of the research paradigm, theoretical framework, addressing both the ontological and epistemological positioning and subsequent methodological tools used to explore Traveller women’s experiences of pregnancy loss (see Figure 3).

This study examines Traveller women’s experiences of pregnancy loss and seeks to explore the personal, interpersonal and structural factors that mediate those experiences. From a theoretical perspective, it is interested in the intersection between, gender, ethnicity and power and how this becomes operationalised within institutions and Traveller women’s interactions with institutional actors. This study draws on an interpretivist, relational, voice-centred, feminist methodology which understands knowledge socially as situated, taking Traveller women's direct experience as the basis for knowledge, a form of epistemic privilege. In doing so, it recognises that Traveller women’s experiences do not occur within a vacuum, but are embedded in a complex web of larger social and structural relationships (Gilligan, 1993[1982]; Mauthner and Doucet, 1998a; Gilligan et al., 2006). The specific methods used are participant structured interviews informed by the biographic interpretive method (BNIM) (Wengraf, 2001) and the voice-centred relational method of analysis. Figure 3 provides an overview of the ontological, epistemological and methodological approaches in this study. The key objectives of this research were to explore:

- personal, interpersonal and structural factors that mediate Traveller experiences of pregnancy loss, and;
- the voice-centred relational method and its contribution to a new understanding of Traveller women’s lived experiences

The chapter begins by providing context to the research, outlining its rationale, aims and objectives, providing a justification for the methodological approach used. This is followed by a discussion of the research design. Next, a discussion on the research paradigm and theoretical underpinnings of this research are provided alongside the ontological, epistemological positioning. This is complimented by describing in detail the data collection and analysis process, including reflexivity, considering current debates on the 'settled gaze' (McDonagh, 2000) which historically has led to the exoticisation, objectification and exploitation of Travellers, specifically Traveller women in academic research (Joyce and Farmer, 1985; McDonagh, 2000). Lastly, this chapter provides a discussion on the ethical considerations of this research, locating them within the broader feminist research paradigm.

5.2 Ontological, epistemological and methodological approach

All researchers hold "highly abstract principles" (Bateson, 1972: 320) which influence their inherent beliefs about the nature of the world and the way in which it may be investigated and interpreted. These *worldviews* (Creswell, 2014: 6), *paradigms* (Lincoln et al., 2011) or comprehensive *research methodologies* (Neuman, 2000; Creswell, 2014) underpin researchers' assumptions about what constitutes, "knowledge (ontology), how we know it (epistemology), what values go into it (axiology), how we write about it (rhetoric), and the processes for studying it (methodology)" (Creswell, 2014: 23). Situated 'inside,' rather than external to our philosophical orientations as Heidegger (1996[1953]: 56) argues, our world views or paradigms guide our investigations, shaping all elements of research (Letherby, 2003; Lincoln and Guba, 2011), including the questions that we ask, the way we choose to ask them and the interpretations of the answers given (Letherby, 2003; Denzin and Lincoln, 2011).

Social science has traditionally offered researchers two competing paradigms: a positivist paradigm[161] that is characterised by a realist ontology and an objectivist epistemology defined by a belief that reality is both external and objective (Lincoln and Guba, 1994, 2008) and a constructionist paradigm. Drawing on the work of Auguste Comte, who believed that the social world can be studied in terms of invariant laws just like the natural world, positivism holds that reality can be measured using systematic observations of nature. Predictability, reliability and deductive reasoning are central to this paradigm, with social reality measured and understood through the value-neutrality of the researcher who sets out to test an *a priori* hypothesis through the application of rigid quantitative methods (Lincoln and Guba, 1994, 2008; Gray, 2004). This particular approach has dominated health-related research, including research on pregnancy loss, as hypotheses regarding causal relationships can be tested and emerging patterns are identified. This allows the researcher to make probabilistic predictions for the future. Focusing intensely on offering technical and deterministic explanations on *what* is

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[161] Creswell (2013:5) notes that this position is often referred to as the "scientific method" or doing "science" research.

occurring rather than developing an in-depth understanding of *how* and *why* it occurs, this approach fails to consider the larger social and structural process which shape human experiences and social realties. This study is fundamentally concerned with the latter, shifting from the conventional approach of explaining the aetiology of pregnancy loss and quantifying experiences, to a more in-depth exploration of *how Traveller women experience* loss. This is not something that can be simply 'stripped of context' (Lincoln and Guba, 1994, 2008) as experiences do not exist within a vacuum and therefore consideration must be given to the specific historical, structural and social milieu within which Traveller women's experiences are deeply embedded (Gilligan, 1993[1982]; Mauthner and Doucet, 2003).

The positivist presentation of research as 'objective' or 'hygienic' (Kelly et al. 2002), that is, orderly, coherent, rational, clean, context-free and removed from all subjectivity is greatly contrasted with constructivist paradigm[162] (see e.g.,Bryman 1988; Hammersley 1989; Stanley, 1991; Phillips 1992; Oakley, 1998; 1999; Kelly et al., 2002; Letherby, 2003; Creswell, 2014). Guided by the writings of Edmund Husserl and Weber, particularly the concept of *Verstehen,*[163] the constructivist paradigm assumes that knowledge is "socially constructed, not discovered" (Flick, 2009; Lincoln et al., 2011: 107). It is within this context that the social world is understood as persistently 'in the making,' and as such, an emphasis is placed on understanding the production of that social world through an inductive[164] approach (Elliot, 2005: 18-19). This paradigm assumes a relativist ontology (there are multiple realties), fundamentally recognising that all knowledge about ourselves and the social world is constructed and contingent on materiality, convention, human perception, and social experience" (Elliot, 2005: 200).

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[162] Also referred to as constructionist and/or constructionism (see e.g.,Holstein and Gubrium, 2008)

[163] .See Schwandt (1998) for overview

[164] Arguing that there is no such thing as 'pure' induction and or 'pure' deduction, Blaikie (2007) proposes two alternative frameworks of enquiry; (1) abductive logic which involves 'abducting' a technical account, using the researchers' categories, from participants' own accounts of everyday activities, ideas or beliefs; and (2) retroductive logic whereby the researcher identifies the structures or mechanisms that may have produced patterns in the data, trying different models for 'fit' (Ritchie et al., 2014: 6-7).

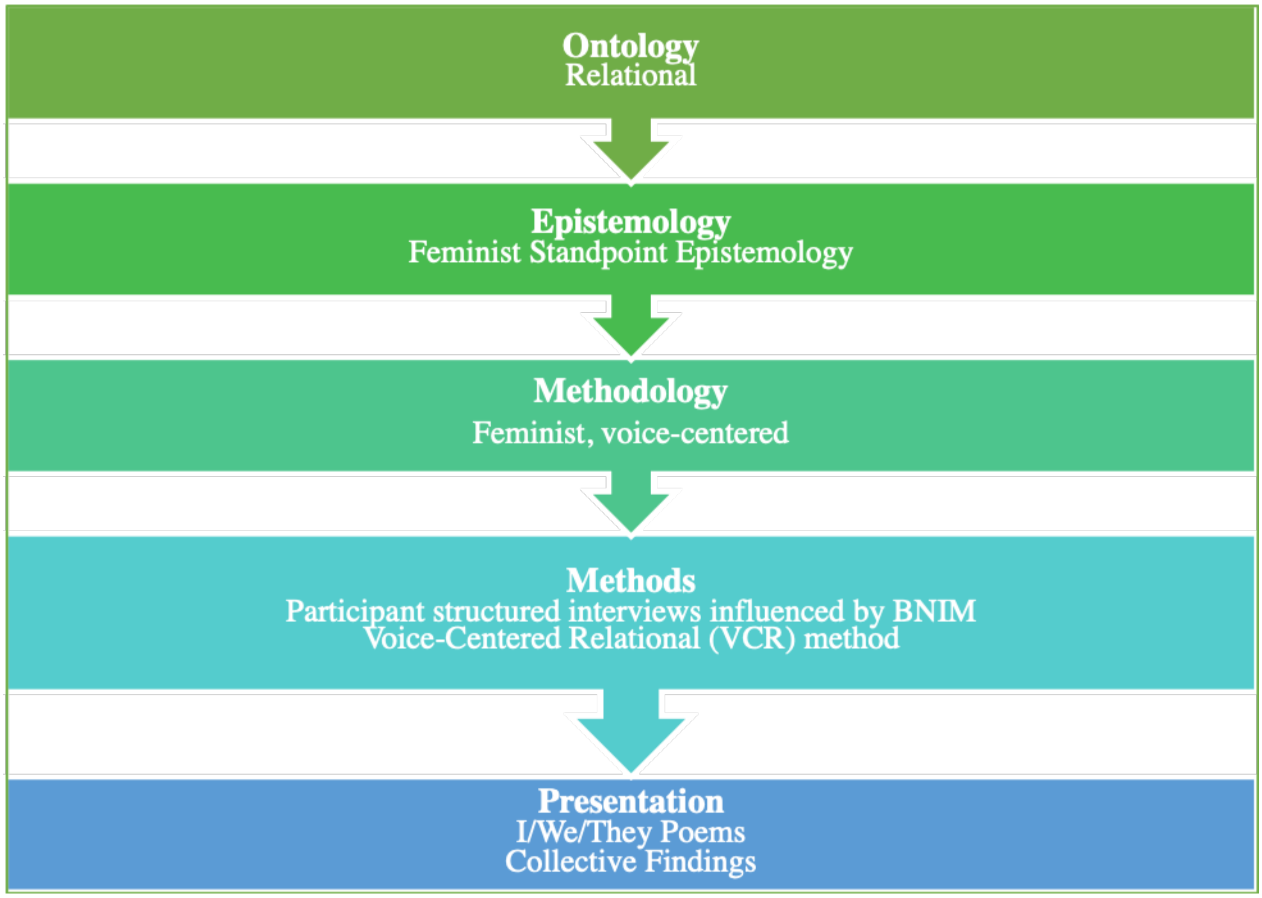

Figure 3: Overview of ontology, epistemology and methodology

5.3 Feminist approach to research

Since the 1970s, feminist scholars have actively challenged positivism as a philosophical framework and more specifically, its methodological tools, or as Reinharz (1984) argues, the "shallowness of its methods, representing a simplistic attitude toward the question of how we can know that something is the case, and its techniques for accomplishing its mission" (Reinharz, 1984: 2). A key critique by feminists was that an existing sex bias existed within the social science, particularly sociology, leading Bernard (1973) to argue:

> Practically all sociology to date has been a sociology of the male world. The topics that have preoccupied sociologists have been the topics that preoccupy men: power, work, climbing the occupational ladder, conflict, and sex- but not women-or women only as adjuncts to men. When women have been dealt with in this sociology of male society, it has usually been in a chapter or a footnote on "the status of women," thrown in as an extra, almost beside the point, rather than as an intrinsic component of a total society. [Bernard, 1973: 782-783]

These dominant modes to research, according to Bernard and others (see e.g., Reinharz, 1984, 1992; Stanley and Wise, 2002[1983]) was the epitome of an androcentric view of social reality

(Stanley and Wise, 2002[1983]: 162). It was within this context that feminists presented an alternative approach to social science research which stressed the need for *listening* to, recording and *understanding* women, 'in and on their own terms' (Oakley, 1980; Gilligan, (1993[1982]); Maynard, 1994; Maynard and Purvis, 1994; Petrovic et al., 2015). According to Stanley and Wise (1990) this basic starting point for feminist research, is that it is beginning from women's lives, also assumed one or more of the following propositions:

> First, feminist research was defined as a focus *on* women, in research carried out *by* women who were feminist, *for* other women. Second, there was a perceived distinction between 'male' quantitative methods and feminist qualitative ones. And third, feminist research was overtly political in its purpose and committed to changing women's lives. [Stanley and Wise, 1990: 21]

Stanley and Wise (1990: 23), in revising their earlier categories of what makes feminist research so distinct, argue that it is the epistemological principles underpinning the behaviour and analysis of the research; outlining five related sites of these in:

1. the researcher-researched relationship;
2. emotion as a research experience;
3. the intellectual autobiography of the researcher; therefore
4. how to manage the differing 'realities; and understanding of researchers and researched; and thus
5. the complex question of power in research and writing

These principles, they argue, must be located in research behaviour and in written research reports by being explicit about our own positionality and intellectual biography. However, the significant question of what constitutes valuable feminist knowledge remains as a pertinent concern for feminist researchers. Again, while a key feature of feminist social research has been grounded in women's experiences, this has been met with critiques by both feminist and non-feminist scholars as it raises fundamental questions in relation to underlying assumptions and conceptualisation of women as homogenous, when in reality this is not the case. In academia, this has resulted in feminist writing primarily reflecting on the experiences and analysis of women from the majority population, specifically women who are Euro-American, white, able-bodied, settled, heterosexual and middle class. This also raises fundamental epistemological issues within feminist research, including the conceptual, theoretical and methodical approaches to our research.

According to Stanley (1991) and others (Harding, 1991; Reinharz, 1992) feminism is not simply a perspective held by researchers, it is both a way of knowing (epistemology) and of being in the world (ontology). Feminist researchers with distinctive research orientations may differ not only in terms of their selection of research methods, but also in the interpretations of the nature of what is being studied and how to best understand the object of study (Stanley and Wise, 1990; Stanley, 1991; Reinharz, 1992).

5.4 Feminist standpoint epistemology

This study is grounded in feminist standpoint epistemology which places Traveller women at the crux of the research process and where women's lived experiences provide the basis in which to build knowledge. As Cockburn (2015) notes:

> Standpoint theory is an epistemology, an account of the evolution of knowledge and strategies of action by particular collectivities in specific social relations in given periods. [Cockburn, 2015: 331]

With its roots firmly located in early feminist movements and drawing on Karl Marx's interpretation of class relations in capitalism, feminist standpoint epistemology emerged in the 1970s in a response to the "brutal history of women's silencing" (Smith 1974, 1981) by authoritative male discourse. However, as Hill-Collins points out (2002) standpoint theory has further developed beyond the original standpoint approaches in Marxist social theory as this was rooted in binary thinking. Feminist standpoint theory, as a general class of theory in feminism, emerged from the work of Sandra Harding who sought a 'radical break' from existing feminist theory by locating knowledge precisely within women's standpoint or in women's experiences (Smith, 1997: 392). This feminist critical theory was concerned with the relations between the production of knowledge and practice of power (Harding, 2004: 1). According to Hill-Collins (1997) standpoint is an "interpretive framework dedicated to explicating how knowledge remains central to maintaining and changing unjust systems of power" (396). As Harding (2004:5) explains:

> Androcentric, economically advantaged, racist, Eurocentric and heterosexist conceptual frameworks ensure systematic ignorance and error about not about the lives of the oppressed, but also about the lives of their oppressors and thus about how nature and social relations in general worked.

Standpoint theory, therefore seeks to see "beneath" dominant discourses and ideologies that have shaped the actualities of women's lives and the conceptual practices of institutions. Standpoint researchers seek to understand and challenge the conceptual practices of power, through which such oppression was "designed, maintained and made to seem natural and desirable to everyone" (6). As Harding (2004: 6) notes:

> Standpoint projects must 'study up;' they must be part of critical theory, revealing the ideological strategies used to design and justify the sex-gender system and its intersections with other systems of oppression, in the case of feminist projects.

A key dimension of ‘studying up’ is through a “collective process of political and scientific struggle” (Jagger, 2004: 57) and with it, a focus on collective experiences and group realities which transcend individual experiences. Therefore standpoint is understood as an explanatory theory, a philosophy, epistemology, methodology and political strategy (Harding, 2004). It further claims that knowledge is always situated, challenging a positivist scientific neutrality, and states that oppression can be a source of critical insight, recognising the knowledge of oppressed groups, especially women (Harding, 2004).

The focus on historically collective based experiences and group realities are key to standpoint theory. However, women are not homogenous, and while early standpoint scholars focused on gender as the defining feature of women's experiences (Smith, 2004), Hill-Collins (2002) argues that the concept of a universal ‘women’s perspective’ presents a ‘racially neutral’ analysis. This, she suggests, ignores critical differences amongst women and perpetuates inequality. Situating her argument within the context of the United States, Hill-Collins argues that African American women share collective experiences that have supported the development of a group standpoint. These collective experiences of differential treatment and material conditions (Hill-Collins, 2000) are rooted in racial inequality and in particular, in a shared history of oppression and segregation. Unlike gender inequality, racial inequalities have been enforced and maintained historically by “a politics of containment that places women in segregated housing, schools, and jobs designed to keep the economic 'bottom” (Hill-Collins, 1998: 210). As she explains:

> US Black women similar work and family experiences as well as our participation in expressions of African-American culture mean that, overall, US women as a group live in a different world from that of people who are Black and female. [Hill-Collins, 2000: 23]

Notwithstanding the heterogeneity and inequality that exists amongst minority ethnic women, Hill-Collins (1997) suggests that African American women’s experiences are located within intersecting hierarches of race, gender and class and therefore the collectivity of African American women as a group has a “degree of permanence over such that group realities transcend individual experiences” (375). Moreover, African American women possess a “unique angle of vision” of the social world (2002: 155), thus facilitating the development of a unique Black women’s standpoint.

As Mauthner and Doucet (2006) point out, the tension in describing feminist standpoint is that there are various interpretations[165] and it has been widely critiqued (Flax, 1990; Walby, 2001) most notably by Hekman[166] (1997) who notes that standpoint theory is a "quaint relic of feminism's less sophisticated past" (341). Other criticisms include the: reification of women; for giving epistemic privilege to gender oppression over other kinds of oppressions (Bar On, 1993), for prioritising the "unique abilities of the oppressed to produce knowledge" (Harding 1991: 57); and for assuming that the standpoints of the oppressed have not been mediated by dominant ideologies (Hawkesworth, 1989, 1999; Flax, 1990; Holmwood, 1995). Acknowledging the critiques from other feminists, Hill-Collins (1997) argues that while standpoint theory recognises the particularity of individual experiences, it is more fundamentally concerned with the ways *social conditions* construct such experiences on a collective group level (375). Distinguishing herself from other standpoint scholars (Smith, 1987) who focus on women's individual 'everyday,' Hill-Collins, drawing on an intersectional lens observes:

> I contend that the collective values in U.S. Black neighbourhoods, when combined with the working-class experiences of the majority of Black women, historically provided collective as well as individual everyday worlds. Thus, U.S. Black culture continually created via lived Black experience with racial segregation provided a social context for the emergence of a Black women's standpoint. Whereas the contexts in which this collective standpoint developed are changing, the purpose or need for it has not. [Hill-Collins, 2002: 292]

This collective experience, particularly that of race, gender and social class, continues to be of primary concern and it is within this context that intersectionality is crucial to understanding the actual mechanisms of institutional power and the ways in which this shapes collective experiences and ways of knowing.

5.5 Relational ontology

Feminist epistemology, according to Campbell (2014:96) is largely defined by its:

1. object of study (feminism);
2. project or collective aims; and
3. commitment to common political and theoretical positions.

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[165] See for example, Smith (1974, 1987, 1999); Hartsock (1983, 1987); Harding (1987, 1991, 1993); Jagger (2004)

[166] See Hekman (1997); Hill-Collins (1997) and Smith (1997) for earlier debates on standpoint

For Harding (2004), the focus of feminist epistemological theory is not to merely, "justify the truth of feminist claims to more accurate accounts of reality," (50), but it is primarily concerned with "relations between the production of knowledge and practices of power" (Harding, 2004: 1). The epistemological focus of this research pre-supposes Traveller women's standpoints (Hill-Collins, 2002) and the lived, subjective experiences of women as the basis for knowledge (Harding, 2004). Standpoint epistemology emphasises knowledge as rooted in women's 'everyday/every night world' (Smith, 1999: 5), with Traveller women's lives and stories as a starting point from which feminist research begins (Harding, 1991: 123). This knower is a social subject, in that social relations form its epistemological position. Traveller women's voices are crucial to this endeavour. However, as Gilligan (1993[1982]) posits, "speaking depends on listening and being heard; it is an intensely relational act" (16). Voice, according to Gilligan, is mediated through language, culture, diversity and plurality. It is relational and exists within relationships which are embedded in a complex web of larger social relations (Gilligan, 1993[1982]; Mauthner and Doucet, 1998a; Gilligan et al., 2006). Gilligan draws on a relational ontology which challenges the assumption of individuals as having a rigid identity that is "ontologically prior to their position in the social world" (Elliot, 2005: 124) and which emphasises the "separate, self-sufficient, independent, rational self or individual" (Gergen, 1992; Mauthner, 1998: 335; Elliot, 2005). Relational ontology instead, is rooted in the idea that relationships form the basis of humanity, as well as our understandings of ourselves.

This study assumes a relational ontology which conceives human existence in the context of societal and personal relationships. A relational ontology presupposes that the 'self' is relationally and interactionally composed and its construction is historically, socially, culturally and contextually specific (Ruddick, 1989: 211; Jordan and Davis-Floyd, 1993: 141). Traveller women's experiences from this perspective are understood as 'interdependent rather than independent' (Tronto, 1995: 142), structured and shaped by their relationships to themselves, to others and to the broader social, political, economic, cultural and policy contexts in which they live. This ontological positioning is particularly suited for this study given that it focuses on the micro, meso and macro-level factors which shape and mediate Traveller women's pregnancy loss experiences. Moreover, it also compliments the basic epistemological underpinnings of this research, that knowledge is socially constructed and situated in the lives of social actors which are embedded within broader social, cultural, political and historical contexts.

5.6 Voice-centred relational (VCR) method

The voice-centred relational (VCR) method is one way in which we can attempt to translate both a feminist stand-point epistemology and relational ontology into a research methodology. The VCR method was initially developed by Lyn Brown, Carol Gilligan and colleagues at the Harvard Project on Women's Psychology and Girls' Development[167] as a direct response to the "uneasiness and growing dissatisfaction with the nature of the coding schemes typically being used at that time to analyse qualitative data" (Gilligan et al., 2003: 157). The method sought to develop and re-define qualitative data analysis by attending to the experiential dimensions of data which could not be captured by the simple organisation of stories and experiences into neat static categories. Initially devised as new 'starting point' for psychological research, the VCR method provided an alternative framework, a 'relational method' for "listening" to interviewees. Rather than simply reading interview transcripts, this method seeks to interpret interview narratives by *listening* to emerging voices (Brown et al., 1991). The VCR method draws from a number of theoretical perspectives – feminist standpoint theory, literary, narrative and relational theories (Brown et al., 1991; Brown and Gilligan, 1992; Mauthner and Doucet, 1998; Gilligan et al., 2006), in addition to the "language of music: voice, resonance, counterpoint, and fugue" (Gilligan et al., 2003: 158).

Based on the premise that 'voice' is "polyphonic and complex" (Brown and Gilligan, 1992: 15), experiencing multiple, sometimes contradictory ways of thinking about and understanding situations. In this approach, how a person speaks (or does not speak) of their experiences, themselves, others and relationships provides insight into their perceptions and experiences (Brown et al., 1991; Brown and Gilligan, 1992; Mauthner and Doucet, 2003). A person's voice is influenced, mediated and potentially silenced by the contexts surrounding the individual, such as societal and cultural frameworks (Brown et al., 1991; Brown and Gilligan, 1992). This approach focuses on the multiplicity of voices embedded in a person's expressed experience (Gilligan et al., 2003; Sorsoli and Tolman, 2008) and as such, the method asks three basic questions; (1) who is speaking and to whom; (2) who is telling what stories about relationship; and (3) in what societal and cultural frameworks? (Brown and Gilligan, 1992: 21).

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[167] According to Gilligan et al. (2003) efforts to make the VCR method systematic began in 1984 and was developed based on Carol Gilligan's (1993[1982]) work on identity and moral development. The approach was undertaken in collaboration with graduate students—diverse in gender, race sexual orientation, and age—over a period of about 10 years (Gilligan et al., 2003: 177). For a detailed overview on the development of this method see e.g.,Brown et al., 1988; Gilligan et al., 1990, 2003; 2006; Brown and Gilligan, 1992; Mauthner and Doucet, 1998b.

Drawing on this initial framework, Mauthner and Doucet (1998b) adapted the method with a sociological lens, exploring individuals' narrative accounts in terms of their relationships to themselves, with others and their relationships to the broader social, structural and cultural contexts in which they live. Mauthner and Doucet's version of the VCR method, represents an attempt to "translate relational ontology into methodology and into concrete methods of data analysis" (156). The VCR method is a systematic approach to data analysis; it is based on a set of flexible guidelines for successively reading and interpreting interview transcripts, each time "listening in a different way" (Brown, 1998: 33). The need for a series of listenings arises, according to Gilligan et al. (2003), from the assumption that the psyche, like voice, is contrapuntal (not monotonic) so that simultaneous voices are co-occurring" (2003: 159).

It is important to acknowledge some of the critiques of voice in qualitative inquiry (Hargreaves, 1996; Atkinson and Silverman, 1997; Jackson and Mazzei, 2009, 2012; Mazzei, 2009). As discussed in Sections 5.2–5.5, early feminist and critical qualitative research emerged in response to positivist and quantitative research paradigms which sought to quantify and measure social realty (Lincoln and Guba, 1994, 2008). This approach sought to privilege voice, to "give" voice to research participants, to bring experiences to the fore, to provide an "authentic gaze" to research participants lives (Atkinson and Silverman, 1997: 305), thus presenting the "mirror of the soul, the essence of the self" (Jackson and Mazzei, 2009: 1). Poststructuralist feminists have questioned the very nature of what constitutes voice (Jackson, 2003, 2009; Jackson and Mazzei, 2009, 2012) particularly given the privileging of voice by qualitative researchers. As Lincoln and Guba (2008: 207) explain:

> As researchers have become more conscious of the abstracted realities their text created, they became more simultaneously more conscious of having readers 'hear' their informants- permitting readers to hear the exact words (and, occasionally, the paralinguistic cues, the lapses, pauses, stops, starts, reformulations) of the informants.

However, as McCoy (2011) argues, "in much the same way that positivist research creates the rhetorical illusion of objectivity, post-positivist work creates the rhetorical illusion of subjective authenticity" (751). St. Pierre (2009: 332) adds to this by questioning the rigour of qualitative inquiry based on "its obsession with the voices of participants as the primary, most authentic data (evidence)" which she argues results in, "the eclipse and disappearance of other data (evidence) that is surely unacknowledged and unaccounted for in a study and, thus, weak analysis and the recycling of old ideas (332). For McCoy (2011), St. Pierre (2009) and others (see e.g., Alcoff, 1991, Lather, 2007, 2009; Mazzei, 2009; Jackson and Mazzei, 2009) the reification of 'voice' as an authentic representation of truth and reality presents clear challenges in the absence of a critical interrogation of epistemologies and power relations in data collection, analysis and presentation (Mauthner and Doucet, 2003; Jackson and Mazzei, 2009: 3; Spyrou, 2011). It also raises key questions in relation to 'interpretive authority' and representation (Guba and Lincoln, 2008). In their critique of 'voice sociology,' Moore and Muller (1999) posit that while researchers intensely focus on ''their self-acclaimed reflexivity'' their lack of reflexivity means that they ''write themselves into their world without stabilising their voice and showing their conditions of production'' (203). Furthermore, they argue that researchers do not reveal how they produce their knowledge which, in effect, is a ''first person narrative of description […] the 'voice' of voice discourse erases the text that writes the world of which it speaks'' (203).

However, as Jackson and Mazzei (2009) caution, the objective should not be to completely abandon a focus on voice; but rather, they urge researchers to deconstruct the epistemological limits of voice by entangling "ourselves in the layers of voices present and the epistemological assumptions that continue to haunt our methodological practices" (3). This includes searching for new ways of considering voice that engages with the very power relations that produces voice (Arnot and Reay, 2007: 312). Both BNIM and the VCR method support this task by providing a framework for 'situated subjectivity' by locating and linking Traveller women's experiences across micro, meso and macro levels. In particular, the VCR method is rooted in a multi-layered treatment of data (Lather, 2007; Jackson and Mazzei, 2012) and in challenging the researcher to extend their thinking beyond what they already know and what they expect, to really listen to the voices of the women in the research. It is important to note that the VCR method is not a "simplistic treatment of voice" that beckon voices to "speak for themselves" or that reduce complicated and conflicting voices to analytical 'chunks' that can be interpreted free of context and circumstance," (Jackson and Mazzei, 2012: 745). The method demands the researcher to "study up, down, sideways and through" (Nader, 1969; Bowman, 2009: 1); to locate participants voices within historical, social and political contexts. It stresses the situated, partial, developmental and modest nature of participants' accounts, as well as their historicity (Mauthner and Doucet, 2003: 424). It also demands researchers to be explicit about the particular epistemological and ontological concepts of subjects that are informing the research practice, the analysis and ultimately the presented research accounts (Mauthner and Doucet, 2003: 424). This means locating themselves in relation to participants; to be methodologically and epistemologically accountable, thus operationalising a reflexive research practice as discussed in the next section and Section 5.21.2.

5.7 Reflexivity and the VCR method

A key tenet of feminist research is reflexivity and the location of the researcher within the activities of her research (Stanley, 1991; 1993; Harding, 1991; 2004; Mauthner and Doucet, 1998; 2002; Stanley and Wise, 2002[1983]). However, this is often limited to the collection of data rather than the interpretive stages of research process. The analysis of research, according to Mauthner and Doucet (1998, 2002) is where power and privilege of the researcher is explicitly apparent and where the ethics of the research practice are particularly acute due to the "invisible nature of the interpretive process" (Mauthner and Doucet, 2002: 130). The authors argue that the notion of a positivistic model of the absent or neutral researcher as 'bricoleur' (Levi-Strauss, 1962: 11) simply carrying out a mechanical procedure of data reduction under an elusive veil of objectivity of what essentially remains a "subjective, interpretative process" is problematic (Mauthner and Doucet, 1998: 122). It is within this somewhat traditional framework that the situated, subjective and 'embodied' researcher carrying out the analysis remains invisible and detached from all interpersonal, social and institutional contexts (Mauthner and Doucet, 2003: 414–415). Agreeing with Alvesson and Sköldberg (2000) and Scheurich (1997), Mauthner and Doucet (2003), instead, posit that data analysis processes, and indeed research projects, are influenced by epistemological, ontological and theoretical assumptions in addition to "personal, interpersonal, emotional, institutional and pragmatic influences" of the researcher (415). It is precisely by locating ourselves as researchers within the interpretive phase that reflexivity becomes tangibly possibly and VCR method is one tool that can be used to deconstruct these issues and operationalise reflexivity within research projects.

5.8 Research design

Feminist research has consistently highlighted the importance of reflecting upon the asymmetrical power relationships including hierarchical power relationships in the research process and relationships between 'researcher' and 'participant.' This is particularly important given the fact that much of feminist research has been focused *on* and *with* marginalised groups. To this end, feminist researchers have insisted on collaborative, reflexive and participatory practices in an attempt to deconstruct inherent hierarchies. As a feminist, I am conscious of the hierarchical power-dynamics which are inherent in all research projects. However, for this study I was acutely aware of the broader context in relation to women and loss and the need not to just listen but to 'hear' women on their own terms. This is something that has been echoed consistently by feminist researchers. I was also cognisant of the broader context in which Travellers and in particular, Traveller women, "have been talked about and talked at" (McDonagh, 2000: 239) both in terms of the analytical frameworks employed by researchers and in the methods. McDonagh adds to this by noting, "as Travellers we have to own research by ensuring that personal narratives become the centre-piece of any research project" (244). While agreeing with McDonagh that the multiplicity of Traveller women's stories must be placed at the centre of research, it is important to acknowledge stories will inevitably become mediated by the researcher, not only in her interpretation of the stories being told but also in the particular tools she has used to elicit those stories. Therefore, it is important to consider both methodological and epistemic accountability.

This study is rooted in a feminist tradition which understands that "knowledge can be produced in structured encounters organized around *telling about experience* (DeVault and Gross, 2014: 209). As such, it seeks to develop an in-depth qualitative understanding of Traveller women's experiences of pregnancy loss in their own words (Hesse-Biber and Leavy, 2006; Hesse-Biber, 2012) and within their particular intersubjective, social and historical contexts. Feminist researchers have used a broad range of forms of interviewing to elicit experiences, this includes structured, semi-structured and unstructured interviews. While the VCR method provides a clear and systematic approach to data analysis, it does not provide any definitive guiding principles on how to gather the data. As noted in the previous sections, the VCR method rests upon 'listening' to participants rather than simply reading interview transcripts. I sought a systematic, participant-led and reflexive method for data collection that could reflect the same principles. It became clear that a biographic-narrative interpretive method (BNIM) style approach would be the most appropriate method for this study.

5.9 Biographic narrative interpretive method (BNIM)

BNIM constitutes both a methodology and method for the analysis of life histories and life stories. The methodology implicit is interpretivist (as indicated in its name) and the analytic method within BNIM is constituted in an intensive 10-stage analytic process of life stories**.** However, as Wengraf (2012: 22) points out, at least half the users of BNIM interviewing procedure do not use 'interpretive apparatus' which reflects the flexibility of the approach. BNIM is a variant of biographic narrative research, as such, it derives from interactionist and phenomenological research orientations. Biography is relational, connecting the individual with the social as a "social construct comprising both social reality and the subjective experiential world" (Rosenthal, 1993: 60). This was imperative for this particular study as Traveller women's experiences of pregnancy loss do not exist in a vacuum, they are created and shaped within structures and social relation.

Sociological biographical research as Rosenthal[168] (2004) explains, began in the 1920s by researchers who recognised the advantages of using a biographical case study for "getting inside of the actor's perspective" (48). This was in the broader context of global shifts, including World War I and II leading sociologists to observe the "inability of sociological theory to account for the massive cultural and political upheavals of the era" (2000: 6–7). C Wright Mills (2000[1959]) in particular, urged sociologists to link biographical experiences to the broader social structure, as the "life of an individual cannot be adequately understood without references to the institutions within which [her] biography is enacted" (161). He goes on to note that people do not exist independently of the structure in which they exist and in order to understand the biography of an individual we must, "understand the significance and meaning of the roles she has played and does play; to understand these roles we must understand the institutions of which they are a part" (161). This is a fundamental ontological position of this study as it understands Traveller women as 'interdependent rather than independent' (Tronto 1995: 142) and structured and shaped by relationships to themselves, to others and to the broader social, political, economic, cultural and policy contexts in which they live.

Biographic narrative approaches were further developed in the 1970s with the Chicago school in its increasing deployment of biography to enhance studies of disadvantaged social groups. This approach centred upon 'giving voice' to those who had been previously neglected in sociological research (Miller, 2000: 6) leading to a 'veritable boom' in interpretive biographical research. The method used in this study, BNIM, was developed from the 'Social Strategies in Risk Societies' research project (SOSTRIS) which was a Europe-wide policy focused investigation into social exclusion (Chamberlayne and Rustin, 1999). BNIM was a principal method used in the project as a way to focus on the experience of individuals who found themselves "excluded, or at risk of exclusion, from important spheres of life in their

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[168] See Rosenthal (2004) for a comprehensive overview of the historical developments of biographical narrative research

societies" (Chamberlayne and Rustin, 1991: 1). Reflecting on the method, Chamberlayne and Rustin (1999) notes that BNIM captures, "the particularity and lived texture of our subjects' lives, at the same time as defining aspects of them which can be seen as typical within a particular social context and history" (44). Again, this is particularly relevant in the context of this study as it seeks derive a holistic analysis of Traveller women's individual and collective experiences of pregnancy loss.

5.10 BNIM interviewing

BNIM interviewing is a participant structured approach, involving at least two, but sometimes three, separate sessions ('sub-sessions') with the interviewee (See Appendix IX). The first sub-session begins with an open, yet, carefully crafted 'single question to induce narrative' (SQUIN) (Wengraf, 2001). At this juncture, the participant is invited to tell her story, beginning where she likes and ending where she likes. The researcher does not interrupt but rather, is *actively* listening and taking notes of key points that are emphasised in particular and key phrases (125). This approach is outlined in Wengraf's comprehensive interview guide (2012) and demonstrates a 'strong tilt towards the silence of the interviewer' (Wengraf, 2001:113). This distinct approach of 'freedom from interruption' means that the participants are provided with the necessary space where participants feel they are being listened to. This approach contrasts more traditional forms of 'question-and-answer' approach which is of particular importance for this study as will be indicated in Section 5.12 below.

The first sub-session is designed to ensure the participant has full control of what was talked about, in what way, to what extent and in what terms (Rosenthal, 2003: 910; Wengraf, 2012: 942). There is a limit of course, to the extent to which participants have complete and full autonomy over this process as they are obviously guided by 'reminder' of the purpose of the interview in the SQUIN which indicates a broad sense of the research interest focus/interest of the study (see Section 5.12) Nevertheless, the participant decides the parameters of what she is willing to disclose or not disclose though her story. As Wengraf reflects:

> BNIM's open-narrative interview structure – as opposed to semi-structured strongly-guiding part-narrative methods – allows or requires the interviewee to give their own form and sequence to what they choose to recall and tell. [Wengraf, 2012: 80]

Once the participant indicates that she is finished, the researcher begins with sub-session 2 which involves asking the participant questions. These questions can only be asked about particular topics that the participant has identified from sub-session 1. The questions must be narrative, in that they are “closed and pointed, aimed to induce a narrative response and to discourage a non-narrative response” (Wengraf, 2001: 127). An example of this could be, “you said that you knew something was wrong at around twelve weeks, can you tell me more about how that all happened?” Participants can decline to answer the narrative questions by ‘not remembering’ or refusing. Their response is respected, ‘listened to’ and not challenged in any way by the researcher. Sub-session three addresses the ‘unmentioneds’ of the first two sub-sessions (Wengraf, 2012). As Wengraf explains, this sub-session is optional and used if ‘something more’ is needed, for example, questions that did not get answered in sub-sessions one and two. This session is considerably more flexible than the first two sub-sessions as it can be fully-structured, semi-structured, or in narrative form. Wengraf recommends that the third sub-session take place after conducting a preliminary analysis from the first two sessions to identify gaps or new questions that have been illuminated from the first two sessions.

5.11 Choosing a BNIM style interview for this study

As discussed in the previous section, BNIM interviewing is a useful method which can facilitate an open narrative interview process. Unique in its approach in eliciting ‘data’ by empowering participants to tell their stories just as they like; to begin, construct and end their on their own terms. BNIM was selected as the most appropriate method for this study as it:

1. creates the necessary conditions for Traveller women to articulate experiences through their own terms without being ‘suppressed’ or ‘micro-managed’ (McDonagh, 2000; Wengraf, 2001, 2012);
2. attends to Traveller women’s lived experiences on individual and collective levels;
3. provides a framework for locating and tracing women’s experiences within the broader structural context; and
4. provides a clear systematic approach to conducting interviews.

More importantly, BNIM style interviewing clearly complimented the VCR method as both provide a framework for ‘situated subjectivity’ by locating Traveller women’s experiences on micro, meso and macro levels; while at the same time providing a framework to understanding collective experiences. This facilitates a rich and holistic analysis of women’s experiences by placing them, as McDonagh notes, at the ‘centre’ (Mauthner and Doucet, 1998b; Chamberlayne et al., 2000; Chamberlayne and Rustin, 2002; Wengraf, 2001, 2012). Aligning with the broader epistemological and ontological positioning of the study, both approaches directly respond to the overall research question, aims and objectives. Lastly, both provide pragmatic methods to operationalise reflexivity which is a key principle of this study.

5.12 Using a BNIM style approach to data collection

As discussed in Section 5.9, the structure of a BNIM style interview has been developed comprehensively by Wengraf (2001) as a way of facilitating an open, narrative interview process. This approach, which involves up to a minimum of two hours, if possible, three hours. Most interviews lasted between in the range of 90 minutes, with some lasting longer (two hours) than others. The first sub-session always begins with a carefully constructed single narrative question aimed at inducing narrative (SQUIN). The single question is broad-based and provides a useful means of eliciting data that empowers participants to begin, construct and end their narrative on their own terms (Jones, 2003; Meares, 2007, Nicholson, 2009). According to Wengraf (2001), this question aims to induce a narrative response and in doing so discourages a 'non-narrative response' such as the "production of a theory, an argument, an unhistorical description, a justification, a declaration of official values or an expression of felt emotions, etc." (127). Drawing on Wengraf's interview guide, I 'reminded' participants of the purpose of the research followed by the SQUIN:

> As you know I am researching Traveller women's experiences of pregnancy loss in Ireland ['reminder']. So, can you tell me your story? ['SQUIN'] I will listen and won't interrupt. I will take some notes if that's okay with you and ask some questions later? Please take your time. Go ahead, begin wherever you like and finish wherever you like

The purpose of the SQUIN question is to maintain the principle of deliberate vagueness which allows the participant to "'impose their own 'systems of relevancy" to their experiences" (Wengraf, 2001: 122). Given that this study is interested in the lived experiences of Traveller women, the SQUIN was open enough to elicit stories based on what women identified as important and relevant to their overall experiences. Again, the power relations remain with the participant as the researcher is required to be silent as Wengraf (2012: 194) notes:

> Unobtrusive supportive (mostly) silent unhurried expectancy - is what you provide after the SQUIN until your interviewee (not you) brings sub-session one to a halt. Allowing and supporting the occasional pauses/silences of your interviewee is important in this respect.

My role as a facilitator was to listen "attentively and sympathetically" (Wengraf, 2012: 194) without interruption or intervening until the participant insisted she was finished. Wengraf (2012) stresses that even if the participant asks for guidance, the researcher must facilitate and not direct, noting: "you destroy the BNIM interview at the moment that you attempt- or consent, to co-steer the interviewee. Instead, the researcher must support the participant; wherever they take their story at whatever length is right (291). The unfamiliarity or uncomfortableness of *not directing* in these particular instances has been highlighted by other BNIM users. However, as Wengraf (2012) points out, it is very rare that participants refuse to narrate and therefore we have to be comfortable with the uncomfortable in this instance.

During Sub-session 1, I remained silent, listening and taking brief notes on specific topics, keywords and phrases that women referred to in the interview. In preparation for Sub-session 2, I took note of what was said at the beginning and at the end of each interview, with specific attention to key words. Once it was clear that the woman had finished her story (e.g.) "that's it; that was all; that's my story" we took a short break. This allowed me to review my notes and to prepare for Sub-session 2, selecting specific cue-phrases[169] that I identified as a "basis for further questioning, further pushing towards more narration, in sub-session two" (197). When we resumed, I asked only about particular things that had been mentioned in Sub-session 1 using Wengraf's 'closed and pointed' approach to eliciting a 'particular incident narrative' (PIN) which I actively pursued throughout the session.

Wengraf stresses the importance staying with the participant; this includes the order in which she had told their story and the language she had used. Maintaining the order in which the participants had told her story is critical, and while there is flexibility to leave some items out of Sub-session2, the researcher must not go back to earlier items as this disrupts the *gestalt* of the original narrative, or as Wengraf (2012) notes, "if you go back, the gestalt goes crack' (292). Using the particular language of the participant is also pertinent, particularly for this study as Traveller women used particular words that I would not have used (e.g.) 'a show' for spotting. For example, "you said you had a show at your mothers. Can tell me more about how it all happened?" Once all PINs had been pursued and were addressed or refused (e.g.) "I can't remember" I began to informally debrief each woman. This was important given the topic in which women were reflecting upon and their experiences disclosed during both sub-sessions. Therefore, at the end of each interview I wanted to acknowledge what each woman had said

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[169] Wengraf (2012: 197) notes that while there are several criteria for choosing 'cue-phrases,' he suggests the following:

1. Where you are trying to understand their subjectivity from the inside for its own sake, then the strongest criterion is to look for cue phrases which strike you as suggesting what is important for them: phrases said with particular emphasis, or strong adjectives or adverbs, assertions of position and attitude, etc. 'Relevance to Them;'
2. When you are working with a firm set of pre-existing theoretical questions then these should also govern your choice of phrases. 'Relevance to your Central research Question'.

and give scope for further elaboration, asking (1) is there anything else you want to add? and (2) how are you feeling?

After each interview, I spent a considerable time debriefing by writing free associative field notes. This was done as soon as possible and was useful in trying to make sense of the interview and later when I began the analysis. It also allowed me to identify some of my own gaps in how I was presenting PINs. This learning was used for further interviews. While initially I envisaged doing three sub-sessions, this didn't occur as the two sub-sessions were sufficient in answering my questions.

5.13 Accessing the field: sampling and recruitment for interviews

5.13.1 Accessing the field

The practical and ethical challenges of carrying out any research, particularly on sensitive topics includes accessing participants who are willing to sit with a stranger and recall personal and potentially painful and traumatic experiences. Recruitment and sampling for pregnancy loss research has generally taken place in either clinical settings, through peer-led support groups, or both. This includes traditional face-to-face support groups as in the work of Layne (1996, 2003) or more recently, online digital spaces (see e.g., McNiven, 2014). Notwithstanding the lack of Internet access amongst Travellers as reported in the national censuses[170] (CSO, 2011b; CSO, 2017) trust was a significant issue to consider. As noted in Chapter 3. the AITHS reported that only 25% of Traveller women agreed that 'generally speaking, most people can be trusted,' this is compared to 68% of women in the majority population (AITHS Team, 2010a: 73). This is also reflected in significantly lower trust levels in health professionals, with only 41% of Travellers reported having complete trust in health professionals, compared to 82% of the majority population. Traveller PHCTPs and Traveller organisations are addressing this gap with 83% of Travellers receiving health information and other information relevant to the broader social determinants of health from Traveller organisations (see Chapter 1).

Again, as noted in Chapter 1, these statistics would not have been possible without the All Ireland Traveller Health Study (AITHS Team, 2010a) which yielded an unprecedented 80%

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[170] The level of internet access for Irish Traveller households is significantly lower than that of the general population. In the 2011 census 71.1% of Travellers reported not having access to internet, this declined slightly in 2016 with 59.9% reporting no access to internet; this compares with 18.3% of the majority population in 2016 and 26.4% in 2011.

participation rate, underscoring the importance of engaging with the Traveller infrastructure as discussed in Chapter 3. This collaborative approach actively engaged with Traveller organisations in the design, collection and analysis of the data and is distinct from previous research which requested ‘access’ to Travellers vis-à-vis Traveller organisations,. While this innovative methodology indicates that sensitive topics such as pregnancy loss can be researched by creating the necessary conditions, it also reflects that collaborative research can be conducted if the researcher is willing to cede complete power and invest time to develop strong and meaningful relationships with the community. This could pro-actively mitigate against what some researchers have described as ‘difficult encounters with gatekeepers’ (Valentine, 2005; McNiven, 2014). For example, McNiven (2014) reflects on her ‘frustrating, drawn-out coordination’ with online pregnancy loss group *gatekeepers,* this included “unanswered or delayed replies to my emails and sometimes ambivalent or hostile responses” (27). My previous research experience in this area emphasised the importance of working with Traveller organisations not only to inform and operationalise an ethical and reflexive research practice but also to ensure buy-in and active participation from Traveller women.

As noted in Chapter 1, my position as a professional working in Pavee Point, contributed to, and constructively shaped this study. Pavee Point’s community development ethos, “nothing about us, without us” underpins any work undertaken by the organisation. This is something that has also been embedded in my work as a professional and is the essence of this study. As discussed in Chapter 1, prior to conducting immersive fieldwork, I spent two years further developing my understanding and analysis of issues affecting Travellers on micro, meso and macro levels. At the same time, I developed close working relationships with colleagues in Pavee Point, including Traveller Community Health Workers who work directly with around 200 Traveller families, or approximately 1,200 Travellers in the Dublin area. These partnerships provided the opportunity to meet with Traveller women to informally discuss the study in various spaces prior to recruitment. Moreover, given Pavee Point’s national remit as one of four national Traveller organisations and the co-ordinator of the National Traveller Health Network (see Chapter 1), I also had an opportunity to connect with other Traveller organisations and Traveller women across the country to discuss the study. It was important to also include Traveller women outside urban regions as several reports and reviews have highlighted the fragmentation of Irish maternity services, including the geographic availability of services and approaches to care.

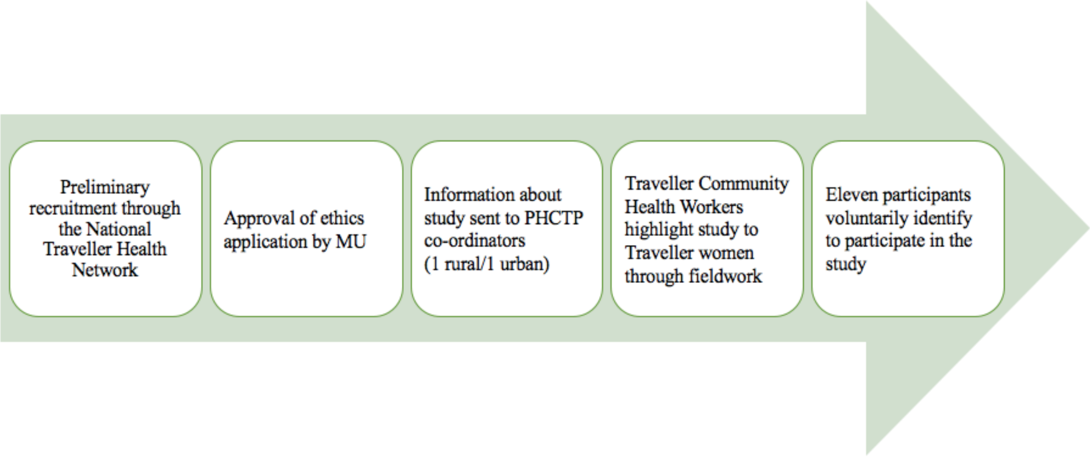

Figure 4: Accessing the field

5.13.2 Inclusion/exclusion criteria

Prior to conducting the interviews, I sought ethical approval from the Maynooth University Social Research Ethics Subcommittee (SREC). While engaging with the Ethics Subcommittee, I was advised that I would have to seek further ethical approval to engage with Traveller women who were currently receiving follow-up care and/or availing of services associated with their pregnancy loss, including those with current psychiatric disorders. This approval would have to be sought from both the Ethics Subcommittee and the relevant maternity hospital/health services they were engaging with. While this raises fundamental questions about women's capacity to make informed decisions about their participation in research projects and who are considered key gatekeepers in this context, the concern of the Ethics Subcommittee was that by including Traveller women in this instance, it could potentially have an adverse impact on their treatment. The Ethics Subcommittee acknowledged that this could restrict the parameters of the research and therefore it was agreed that recruitment would begin with participants who were not currently receiving treatment, but may have had treatment in the past. If it became imperative thereafter then the Ethics Subcommittee would consider an additional application. Once interviews began, it was clear Traveller women weren't engaging in any follow-up services and therefore a further ethics application in this regard was not required.

The Ethics Subcommittee also advised that recent experiences of pregnancy loss should inform part of the exclusion criteria, with a minimum time period applied. As a result, Traveller women who experienced pregnancy loss in the four months preceding the interview were not included. This time frame allowed for relatively contemporaneous experiences, pertinent to the research objective. It is within this context that the inclusion criteria for the study were Traveller women, over the age of 18, who had experienced pregnancy loss in Ireland. The exclusion criteria were Traveller women who:

- were currently pregnant;
- had a current diagnosis of depression and/or any other psychiatric illness associated with their pregnancy loss; and
- were receiving follow-up care associated with that pregnancy loss.

5.13.3 Selecting a sample

Selecting a sample for this study was critical as I sought to ensure a broad range of participants in order to reflect the 'multiplicity' and heterogeneity of Traveller women's experiences, attention was given to age, marital status and geographical location. However, at the same time I was cognisant of my particular methods for data collection and analysis, both of which are labour intensive and required considerable investment in time. I did not want to interview Traveller women to fulfil a quantitative purpose. I set a tentative target to interview ten Traveller women, excluding the pilot interviews. An additional four Traveller women initially agreed but were unable to commit time to participate in the interviews.

5.13.4 Recruitment

Formal recruitment took place following ethical approval from Maynooth Social Research Ethics Subcommittee. I disseminated the study information sheet (Appendix X) to two PHCTPs (one urban and one rural) and had further discussions on recruitment. It was clear that a conventional approach to recruitment whereby information sheets are disseminated and potential participants contact the researcher to discuss participation would not work given the low literacy levels and the sensitive nature of the study. Therefore, PHCTP co-ordinators discussed the study with Traveller Community Health Workers in their projects who discussed the study with Traveller women during fieldwork and reverted back if a woman was interested. Nine Traveller women were recruited through this approach and two were through snowballing from this process (See Figure 4). The women recruited for this study reflect a breadth of experiences spanning the course of 30 years. Women are diverse in terms of age, geographical location, type of pregnancy loss, the time period/decade of the pregnancy loss, their marital status, and the ethnicity of their partner (see Table 1).

Table 1: Details of interviewees

	Pseudonym	Type of pregnancy loss	Time pregnancy loss occurred	Relationship status at time pregnancy loss	Ethnicity of father
1	Megan	Early neonatal death and miscarriage	1990s	Not married	White Irish
2	Rosie	Early neonatal death	2010-	Married	Irish Traveller
3	Catherine	Miscarriage x 2	2000/2010	Not married	White Irish
4	Eileen	Miscarriage x 2	1980s/1990s	Married	Irish Traveller
5	Deirdre	Miscarriage	2010s	Married	White Irish
6	Molly	Miscarriage	2000s	Married	Irish Traveller
7	Kelly	Miscarriage	2000s	Married	Irish Traveller
8	Alice	Miscarriage x 3; Stillbirth	1990s	Married	Irish Traveller
9	Caroline	Early neonatal death and miscarriage	1980s/2000s	Married	Irish Traveller
10	Linda	Miscarriage	2010-	Married	Irish Traveller
11	Joanne	Miscarriage x 2	1990s	Married	Irish Traveller

Table 1 Description of all interviewees. Those highlighted were selected for case analysis and poem presentation in Chapter 6.

5.14 Piloting interviews

Given that this is the first study to use a BNIM style interview approach specifically to explore Traveller women's pregnancy loss experiences, it was imperative to conduct pilot interviews to ensure women were comfortable in this somewhat unconventional approach to interviewing and to further develop my capacity in facilitating this particular interview style. Prior to conducting the pilot, I conducted a 'pre-pilot' by convening a small focus group in Pavee Point with Traveller women. The purpose of the focus group was to discuss the interview format, propose follow-up questions and to review any written materials that would be distributed during the interviews (See Appendices VI–VII). Feedback from this session was used to inform the pilot interviews and eventually the interviews that took place thereafter.

Pilot interviews were conducted with three Traveller women. This rationale for the pilot was to inform my approach to interviewing, particularly in reformulating the ways in which I proposed PINs in Sub-session 2. Pilot interviewees also reviewed the written materials and provided comprehensive feedback. Given that the pilot interviews were effectively a simulation exercise used to prepare for actual interviews, I conducted them just as I would a real interview, recording the audio, transcribing verbatim the interview and initiating the analysis. With permission from interviewees, I also reviewed the transcripts in consultation with my supervisor who is trained in BNIM and was a critical reference point in refining my approach to subsequent interviews.

5.15 Conducting interviews

BNIM style interviews were conducted with eleven Traveller women, in two diverse field sites; one urban field site adjacent to a maternity hospital and a rural field site close to a maternity unit co-located with an adult acute hospital. Immediately prior to conducting the interviews, I briefed each woman on the style of the interview and reviewed the research information sheet and consent form, reading over the forms with each woman (Appendices X-XI). This was to ensure that women were providing consent on basis that they were informed of the research aims, objectives and the ways in which their words and stories would be used. It was also a way to mitigate any issues with literacy in obstructing women's decision to participate in the study. We discussed anonymity and confidentiality, including the limits to both, as outlined in the Maynooth University Research Ethics Policy (Maynooth University, 2016). Each woman initially provided written consent which was confirmed again via audio recording.

Each interview lasted between 90 minutes and two hours, taking into consideration short breaks in between sub-sessions 1 and 2 and the fact that some women spoke for longer periods than other. Interviews were conducted in a location of the women's preference, which included their homes, places of work and community centres. All interviews were audio recorded (with the women's consent) and transcribed verbatim. However, given that audio transcripts cannot capture non-verbal communication (e.g. significant pauses, long exhales, laughter, anger, tears, etc.) I noted specific information in relation to the environment during the interview and in the free associative debriefing notes, listening to each audio recording again before I began analysis to elicit memories of the interview. I did this a number of times throughout the research process. This was beneficial during the analysis and interpretation phase, and in particular, case development as a part of the analytical process.

5.16 Post-fieldwork methods

Lastly, upon completion of data collection the field I stored all of data securely, this includes interview notes, transcripts, debriefing notes, consent forms, audio files and/or any other data pertaining to the study were password protected and stored on desktop PC. Data collected on a mobile device, particularly audio recordings, were encrypted and were password protected. Following each interview the files were transferred to the desktop PC and deleted from the device. This was to ensure that data, and by extension, women's confidentiality and anonymity were not compromised as per the Maynooth University Research Ethics Policy (Maynooth University, 2016) and in line with data protection legislation.[171]

5.17 Choosing the VCR method for this study

While a method cannot be inherently feminist (Maynard, 1994), the rationale of using a narrative approach to data collection analysis is part of a commitment to feminist research practice (Letherby 2003; Sharp 2005), placing women's narratives at the centre of analysis (McDonagh, 2000). Furthermore, this research is intended as part of wider feminist praxis to hearing women's voices by attending to women experiences (Etter-Lewis, 1991) and more specifically, to contribute to 'breaking the silence' surrounding pregnancy loss (Cecil, 1996a, 1996b; Layne, 1997; 2003a; 2003b). According to Riessman (2000) personal narratives, or 'storytelling' is "a relational activity that gathers others to listen and empathise. It is a collaborative practice, and assumes tellers and listeners/questioners interact in particular cultural milieu—historical contexts essential to interpretation" (3-4). This study is focused on women's voice and aims to uncover the multiple layers and 'voices' of Traveller women; it is also concerned with the structural aspects of Traveller women's stories, specifically, the broader historical, social, policy and structural contexts which shape women's felt experiences of pregnancy loss. As outlined in the preceding section, the VCR method facilitates a holistic analysis of Traveller women's stories by bringing together the micro, meso and macro processes which have informed and been superimposed upon Traveller women's experiences.

5.18 Translating the voice-centred relational (VCR) method into practice

Despite requiring very few materials (colouring pencils, interview recordings and verbatim transcripts), the time dedicated to the VCR method cannot be understated, as it involves three to four[172] detailed 'listenings,' or more commonly referred to as 'readings' of the same interview transcript (Mauthner and Doucet, 1998a, 1998b, 1999, 2002, 2003). This structured

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[171] In 2018, the Data Protection Act 2018 was signed into law based a European regulation, the General Data Protection Regulation (GDPR). The Act amends the previous data protection framework, which was established under the Data Protection Acts 1988 and 2003. The enactment of this legislation did not affect data collected for this study as rigorous standards were applied following throughout the research process following the United Nations Human Rights-Based Approach to Data (OHCHR, 2018])

[172] Brown et al. (1991); Brown and Gilligan (1992); Gilligan, 1993[1982]; Mauthner and Doucet (1998a, 1998b, 1999, 2002, 2003) suggest listening to a person's story at least four times to trace the different voices and orchestrations throughout the interview .

framework and lengthy focus on individual interviews is what distinguishes the VCR method from other methods of qualitative analysis (Mauthner and Doucet, 1998b; Paliadelis and Cruickshank, 2008). Each reading requires the researcher to trace different voices through the interview, tuning her ear to particular aspects of the narrative. Mauthner and Doucet (1998b; 2003) advocates for a flexible approach to the number and types of readings that can be done, contingent on the aims and objectives of the research. Given the substantial amount of time it takes to conduct a full VCR method analysis, it would have been impossible to conduct all four readings with each and every interview with due diligence and therefore, I focused my attention on three interviews for a full VCR analysis and used them to develop case studies.

For each interview, however, I conducted reading 1 and 2 of the method (Mauthner and Doucet, 1998b). I developed short summaries of each interview using the VCR framework to address each dimension of the interview, and this was supported by the 'I/We/They' poems developed from Reading 2. Following this, I conducted an overall thematic analysis of the data set as a whole based on themes and sub-themes which emerged as a direct result of the case study. This provided a link from individual stories to collective stories as told by the data sets as wholes. The rationale for conducting two initial readings of the interviews was to:

1. develop an in-depth understanding of each woman's story, how she speaks about herself and my response to her story;
2. connect individual stories to the overall research question; and
3. to identify three interviews that could be used to illuminate the overall findings and respond to the research question.

Although not all interviews were processed through the entire VCR method, the remaining interviews provided the necessary context for selecting the three stories for a case development. Moving between analytic angles was useful in illuminating the particularities specific to each woman's story, while at the same time revealing common threads that tie their experiences together collectively (Edwards and Weller, 2012). The case development represents the varying analytic angles and implicit ontologies reflected across all Traveller women's narratives.

5.18.1 Selecting cases for full VCR analysis

In selecting the cases, it was important to develop a clear justification as to *why* these particular cases were chosen and not others. As noted in Section 5.13.4, Traveller women in this study reflect a breadth of experiences spanning over the course of 30 years. Women were diverse in terms of age, geographical location, type of pregnancy loss, the time period/decade of the pregnancy loss, their marital status, and the ethnicity of their partner. I was interested in exploring Traveller women's experiences across this time period, in the context of considerable socio-cultural and policy shifts, specifically as it related to women, Travellers and Traveller women. I was also interested in tracing shifts in practice by exploring Traveller women's experiences of health services over this period. After careful consideration, three cases were selected on the basis of 'difference' (Chamberlayne and King, 2000) with age, interpersonal relationships[173] and time period in which loss occurred. The following sections provide further detail of the analysis process used for the cases, outlining each step required for overall analysis. Using a typology proposed by Mauthner and Doucet (2003), I organised each of the four readings accordingly to the type of narrative elicited. As such, Reading 1 focuses on Traveller women's reflexively constituted narratives; Reading 2 traces Traveller women's ontological narratives; Reading 3 focuses on their relational narratives; and finally, Reading 4 attends to the conceptual narratives. Each are described in detail below.

5.19 VCR method analysis

5.19.1 Reading 1: relational and reflexively constituted narratives

This initial reading focuses on the plot and for our responses to the narrative (Mauthner and Doucet, 1998). It is predicated on the basic question 'what is going on here?'(Mauthner and Doucet, 1998). It is also interested in (1) who is telling the story; and (2) who is listening (Byrne et al., 2009: 69). I started the process by reading each transcript to elicit my own memory of the interview. I then listened to the audio file while simultaneously reading the written transcript, listening for the plot – the who, what, when, where and why of the narrative attending to 'what is happening' and 'what stories are being told' (Mauthner and Doucet, 2003). Using various coloured highlighters, I traced the central storylines in the form of recurring words, themes, events, chronology of events, protagonists, plot, subplots, key characters and contradictions (Mishler, 1986; Elliott, 2005; Mauthner and Doucet, 2008). I attended to the multiple contexts, both spatially and temporally, within which Traveller women's stories were embedded (Brown and Gilligan, 1992; Gilligan et al., 2003) in addition to repetition of images, metaphors and/or other major themes. As outlined in the proceeding chapters, this first reading revealed a collective story of pregnancy loss as a traumatic life event which is incredibly painful and distressing, impacting on Traveller women's identity and

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[173] This refers to Traveller women's interpersonal relationships with their partners or ex-partners (boyfriends, fiancés, husbands)

esteem. This is told through shared stories of loss; including loss of baby and an imagined future, loss of self-identity, loss of vitality, loss of bodily autonomy and loss of confidence in medical professionals.

Mauthner and Doucet (1998b) encourages researchers to explicitly document how theoretical interpretations of narratives are made. As a non-Traveller woman listening to Traveller women's stories, I was cognisant of and concerned about responses both emotionally and intellectually to each woman's story. Therefore, in addressing the second question, that is, who is listening, I read for myself consciously in each transcript. I attended to my own voice and allowed my subjectivity and feelings to emerge as explicit from the beginning by "identifying, exploring and making associations (or not) with" (Gilligan et al., 2003: 162) the narratives being analysed. According to Mikel Brown (1994):

> The first listening or reading requires the listener/interpreter to consider her relationship to the speaker or text and to document, as best she can, her interests, biases and limitations that arise from such critical dimensions of social location as race, class, gender and sexual orientation, as well as to track her own feelings in response to what she hears - particularly those feelings that do not resonate with the speaker's experience. [392]

Mauthner and Doucet (2003) add to this by noting the need to recognise the interplay between "multiple social locations and how these intersect with the particularities of our personal biographies as far as possible, *at the time* of analysing data" (419). I used this reading to explore the way in which my position as a non-Traveller woman who has not personally experienced pregnancy loss might influence my interpretation of women's accounts. According to Mauthner and Doucet (1998b):

> The underlying assumption here is that by trying to name how we are socially, emotionally and intellectually located in relation to our respondents we can retain some grasp over the blurred boundary between their narratives and our interpretations of those narratives. If we fail to name these emotions and responses, they will express themselves in other ways such as in our tone of voice or the way in which we write about that person. [130]

On a practical level, I followed Gilligan et al. (1990) and Brown and Gilligan (1992) by using a template similar to the Cornell Notes system by inserting Traveller women's words in one column and my reactions and interpretations in an adjacent column (Gilligan et al. 1990; Brown and Gilligan, 1992). I included a column at the bottom of the page to write up a short synopsis of my reactions based on my multiple positions, as a woman, as a non-Traveller woman, as a researcher, and as a professional. This was extremely valuable as it allowed me to identify the multiple locations in which I framed my assumptions and views in relation to women's narratives. For example, I responded directly to socio-emotional and personal aspects of women's narratives, attuning my ear to the ways in which women *felt* about the ways in which they were treated by health services (e.g. infantilised, silenced, excluded etc.). As a professional, I tended to respond directly to the interpersonal and structural dimensions, what I heard as gaps in policy and in practice. I also noticed that I listened for the ways in which health services and Traveller organisations were visible or invisible in Traveller women's narratives and to understand where gaps, if any, existed.

5.19.2 Reading 2: tracing Traveller women's ontological narratives

This stage of the data analysis seeks to reveal respondents' different subjectivities, multi-layered voices, views and perspectives by attending to the active "I" represented in the story. It does so by tracing how the participant experiences, feels and speaks about herself in the interview within the parameters of her social world. According to Mauthner and Doucet (1998b) this is a key feature which distinguishes a VCR method of data analysis from grounded theory as it is intensely interested in a person's different subjectivities and sense of self, as opposed to focusing entirely on her action/interactions. Focusing on Traveller women's stream of consciousness, I carried out this reading by locating all references to the first person. Again, on a practical level this involved using a highlighter to trace the active 'I' in each interview, specifically where she used personal pronouns such as 'I/you/me', 'we' or 'they' in talking about herself. This was accompanied by a verb or seemingly important accompanying text. In developing the I-poem, I:

1. highlighted every 'I' phrase within a given passage; and
2. recorded these phrases in the order of their appearance in the passage.

The rationale for this is to highlight where the participant might be emotionally or intellectually struggling to say something (Mauthner and Doucet, 1998b). According to Mauthner and Doucet (1998b), such focused attention on the voice(s) of the 'I' "increases the possibility of creating more or less space within which to hear our respondents' voices" (132). Adding to this, Brown and Gilligan (1992) note that listening for this voice is crucial as it, "brings us into relationship with that person […] discovering how she speaks of herself before we speak of her" (16).

After initially highlighting each personal pronoun in different colours, I constructed three poems for each woman; 'I' poems, 'we-poems' and 'they-poems.' 'I' poems were used to understand how Traveller women represented themselves and their experiences. 'We' poems revealed how Traveller women spoke about their interpersonal relationships, in particular intimate relationships with partners and family members. While ‘I’ poems and to a lesser extent, ‘we’ poems are a distinct feature of the VCR method, I was also interested in how ‘they’ poems could contribute to a new understanding of Traveller women’s relationships and overall structural experience. While ‘they’ was used to identify particular institutional actors (e.g.) doctors, nurses, etc., it was also used to denote health services and broader institutions. I extracted the pronouns and accompanied text, placing them in separate lines in the same sequence as they occurred in the interview, mirroring a poem (see Chapter 6). From here, I organised the poems into stanzas, keeping them in chronological order as I wanted to stay with the structure in which each woman presented (Edwards and Weller, 2012). I then reviewed the poems and identified ‘voices’ which were evident in the poem. While some of these voices appeared unique to each of the three narratives selected for the full VCR analysis, other voices were echoed across all narratives. This includes the *ignored voice*, the *grieving voice* and the *resilient voice*. Interestingly, Traveller women associated each voice with age, maturity, experiential knowledge and in some instances, professional knowledge.

5.19.3 Reading 3: tracing Traveller women’s relational narratives

Recognising the relational aspects of Traveller women’s narratives, the third reading of the VCR method shifted its focus from the individual, to her social networks and intimate relations. Drawing on Gilligan et al. (2003) and Bright (2016), the questions that guided this reading included:

1. Who is spoken about (relationships, emotions, statements and stories)
2. Who is related to who in what way?
3. How are people positioned within the relationships and interactions?
4. What are people saying and doing (acting)? How do they expect to act?
5. How do they do things and how did they develop that knowledge?
6. What roles are Traveller women playing?
7. How do they perceive situations, words and actions (symbols)? How does this impact on Traveller women’s actions?

As such, I listened for how Traveller women spoke about their interpersonal relationships with their partners, immediate families, health services and other institutions. Using both the ‘they-poems’ from the previous reading, I traced women’s words as they spoke about their relationships and identified social networks. This was extremely useful in revealing Traveller women’s perceptions of ‘support’ and ‘care’ as being provided exclusively by intimate relationships and close social networks as indicated in their ‘we-poems.’ This was juxtaposed in women's 'they-poems' as health services and institutional actors were generally constructed as 'unsupportive' and 'careless.' There are examples, however, in which Traveller women describe some positive experiences with specific staff, specifically nurses, midwives and chaplains/priests. Nevertheless, these relationships are constructed as unique and based on a personal motivation rather than a professional obligation, as further discussed in Chapter 7.

5.19.4 Reading 4: tracing Traveller women's conceptual narratives

This reading is concerned with linking micro-level narratives with macro-level processes and structures (Mauthner and Doucet, 2003). In doing so, it focuses on Traveller women's conceptual narratives by:

> Reconstruct[ing] and plot[ting] over time and space the ontological narratives and relationships of historical actors, the public and cultural narratives that inform their lives, and the crucial intersection of these narratives with other relevant social forces. [Somers, 1994: 620]

Traveller women's narratives were listened to in the context of the specific cultural and political contexts and social and economic structures in which she is located, and which shapes her sense of self. I was interested in Traveller women's 'webs of interlocution' (Taylor, 1989: 36; Benhabib, 1995) that is, the grand or macro-level narratives in which women were structurally located within and in which shaped their micro-level experiences. Drawing on Mauthner and Doucet (1998a, 1998b) I asked the following: what are the broader social, political, economic, structural issues surrounding Traveller women's stories, experiences, actions and interpretations?

The time period in which all three cases were selected coincided with major social, economic, political and policy shifts, including policy related to Travellers (see Chapter 3). With all three cases occurring within periods of recession or intense recovery, specifically, the economic crash which had devastating impact on Traveller organisations and PHCTPs as discussed in Chapter 3. There were also broader shifts in reproductive politics with the landmark ruling of the X Case, which emboldened national discourse on women's sexual and social identity and gave rise to an intensely divisive debate on abortion and most recently the referendum on repealing the Eighth Amendment to the Constitution (Hesketh, 1990; Smyth, 1992a, 1995, 1998; Murphy-Lawless, 1993; Oaks, 2002) (see Chapter 2, Section 2.7).

All three cases also reflect significant shifts in maternity care and socially in terms of pregnancy loss (see Chapter 2). I was also interested in the structured power relations and dominant ideologies that frame Traveller women's narratives, and in particular, how sexism and racism intersect and shape women's experiences within the broader context of Traveller policy, maternity policy and institutional practices. While at the same time, for Travellers, these periods were fundamental in the development of Traveller focused policy, with the publication of the Task Force Report, the National Traveller Health Strategy, the AITHS and number of developments within the Traveller infrastructure[174] (Fay and Crowley, 1989; Government of Ireland, 1995; O'Connell, 1996, 1997; Fanning, 2009). This reading revealed that, despite considerable shifts in policy and obstetric practice over a thirty-year period, Traveller women continue to feel constrained within institutional settings and in their interactions with institutional actors. Travellers situate themselves and are situated within and against relations of power on micro, meso and macro levels.

5.20 Composing an analysis and presenting findings

Following all four readings for the three interviews, I developed detailed case studies. This allowed me to get closer to each of the three women's stories and to develop a deeper understanding of each of their distinct experiences. It also allowed me to become familiar with the similarities between the cases as well as the significant differences. Further, given the selected time periods of pregnancy loss (1990, 2000s; 2010s) for the cases, it allowed me to focus attention on the conceptual narratives which was useful in supporting the development of the overall collective analysis and make connections between the micro/meso and macro structures and processes.

I then reread the remaining narratives listening for the issues or voices I had identified in the case studies which was critical in terms of understanding the experiences of our respondents. I then reviewed the data set as a whole and found this was the most challenging aspect of the method, given the large volumes of data and the various dimensions to work with (e.g. audio recordings, field notes, transcripts, summaries, four readings, case studies, themes/sub-themes). I also found that flexibility was the most challenging as I wanted more guidance on how to integrate the case studies and thematic analysis readings more holistically. Using Mauthner and Doucet's (1998b) flexible guide, to reflect on Traveller women's 'stories', 'voices' and 'self,' I returned to the initial research question and asked myself:

1. What has been learned about Traveller women in relation to the research question?
    a. How do Traveller women experience pregnancy loss on an individual level?

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[174] See Chapter 3 for further information

    b. How do Traveller women experience pregnancy loss on an interpersonal level?
    c. How do Traveller women experience pregnancy loss on a structural level?
2. What have you learned overall about this question through the process? How have you come to know this?
3. What is the evidence on which you are basing interpretations?

This structure formed the basis for the overall analysis presented in Chapter 7 as the 'collective narrative,' or 'common stories told' articulated by Traveller women. These collective stories are those which appear consistently throughout what women have identified as the three stages of the pregnancy loss experience, that is, before, during and after loss. In reflecting upon the data set as a whole (Mauthner and Doucet, 1998a, 1998b), it was clear that loss emerged throughout each story. This includes the loss of baby and an imagined future, loss of self-identity, loss of health and well-being, loss of bodily autonomy and loss of confidence in medical professionals. In presenting the findings, I was conscious of the ways in which all Traveller women described feelings of being silenced and dismissed during and after their pregnancy loss. This was particularly clear upon analysis of the second reading and development of 'I/We/They' poems which are told through the (1) ignored voice; (2) grieving voice; and (3) resilient voice. Reflecting on the ontological and epistemological positioning of this research, I was interested in staying with women's voices, in their own terms. As such, Chapter 6 presents three distinct stories told in the form of poems. The poems have been developed from the three case studies, with each poem illuminating the personal, interpersonal and structural dimensions of Traveller women's experiences. The poems are an attempt to *stay* with Traveller women and in doing so, illuminate "how she speaks of herself before we speak of her" (Brown and Gilligan, 1992: 27–8).

5.21 Ethical considerations

One of the most challenging aspects of conducting research is ensuring and operationalising an ethical research practice both methodologically and theoretically. The significant responsibility of the researcher in this regard cannot be understated, particularly in the context of research that delves into the most intimate and personal aspects of people's lives, making them public for others to also to interpret and theorise. This is of course further compounded by a historical legacy of voyeurism and exploitation, often under the guise of social scientific 'research,' particularly for indigenous and minority ethnic groups, including Travellers. Beyond numerous examples of modes of data collection including moving onto Traveller camps and sites[175] to capture the 'authenticity' of the research field (McCarthy, 1972; Gmelch, 1975, 1985; Helleiner, 2000, [1961]), previous researchers have also neglected the politics of knowledge production and representation of Travellers (McCarthy, 1972; Gmelch, 1975, 1985). As a consequence, a legacy of Traveller focused research exists within academia (whether intentionally or unintentionally) which has been frequently used to create, perpetuate and enforce anti-Traveller racism. Nan Joyce, for instance, has written about how "foreigners coming and writing books about us: some books are very hurtful – the people who write them should be sued" (Joyce and Farmar 1985: 116). McDonagh (2000) adds to this by noting:

> Over the years researchers have used me and other Travellers in ways that I know would not be tolerated by settled people […] we as Travellers were being used in order to provide information. That information was then interpreted and written in a way that excluded us from our own experience […] We were used in feminist discussions only as a tool for defining poverty and exclusion and an image was portrayed of us as being locked into a tradition that located women perpetually in a subordinate position in a patriarchal culture. The dominant culture was using us as an example of being victims of our own tradition by our refusing to assimilate or be settled. This voyeurism is still considered a norm among some feminist researchers. [McDonagh 2000: 237-239]

As McDonagh points out, the ethical protocols of research must extend beyond the methods of data collection and include questions around epistemic responsibility and accountability. While I followed key ethical principles outlined by the Sociological Association of Ireland and the Association of Social Anthropologists, as McDonagh notes, such a code of conduct is of little use "when Travellers are in a passive role" (245). Therefore, it was fundamentally important to my overall approach that the 10 Common Basic Principles on Traveller and Roma Inclusion[176] (European Commission, 2009) were embedded in this research from the very beginning; this includes the overall approach to the research and the research design as reflected in Chapter 1. As result, I made a clear commitment to working in solidarity and

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[175] This is not unique to Ireland, for example, anthropologist Judith Okley (1998[1983], 2014) details her experience living amongst Gypsies on encampments over a number of years. According to Okley (2014) this experience legitimizes her research allowing her to speak from place of authority: "the insights from social anthropology draw upon long-term participant observation, ideally co-residence for a year or more. The anthropologist derives specific authority from individual fieldwork (Okley, 2014). In this case, the author's in-depth experience entailed living among the Gypsies on several encampments from the 1970s, in addition to follow-up visits amounting to over two years" (Okley, 2014: na70).

[176] The Common Basic Principles were presented at the meeting of the European Platform for Roma inclusion in Prague on 24 April 2009. The Council of Ministers in charge of Social Affairs annexed the Principles to their conclusions and invited Member States and the Commission to take them into account. The 10 Common Basic Principles on Roma Inclusion (which is inclusive of Irish Travellers) provides a framework for the design and implementation of actions to support Traveller and Roma inclusion in policy, research and other relevant projects. The principles are as follows (European Commission, 2009):

1. Constructive, pragmatic and non-discriminatory policies
2. Explicit but not exclusive targeting
3. Inter-cultural approach
4. Aiming for the mainstream
5. Awareness of the gender dimension
6. Transfer of evidence-based policies
7. Use of European Union instruments
8. Involvement of regional and local authorities
9. Involvement of civil society
10. Active participation of Travellers/Roma

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partnership with Traveller women and Traveller organisations at every stage of the research process.

Nevertheless, it is not always clear how to address such issues as both academic and professional ethics committees alongside research textbooks frequently provide standardised ethical rules such as gaining/maintaining informed consent, privacy/anonymity, avoiding harm, safety and storage of data, and spoiling the field/rapport (Neuman, 2000; Silverman, 2007). Notwithstanding the importance of adhering to these rules in principle, their prescribed nature and rigidity in many ways obscures the messiness and complexity of qualitative research. As Birch et al. (2002) note, "principles guide our perceptions of how to conduct ethical research and yet, specific circumstances and contexts inform our decisions" (6). As a consequence, the tick-box approach to ethics leaves very little room for 'contextualised methods of reasoning' (Holm, 1997; Edwards and Mauther, 2002) and meaningful discussions about ethical ways of thinking in *all* stages of the research process. This leads Birch et al. (2002) to argue, "the constant neglect of detailed ethical discussions in all stages of research projects renders the enterprise open to being unethical." (5). The following sections discuss such ethical considerations.

5.21.1 Ethics: methodological accountability

As noted in Section 5.15, Traveller women were provided with clear information about the study prior to the interview; this included information in relation to the research question, aims and objectives. Immediately before each interview I briefed each woman again about the study including the somewhat unconventional approach to the interview, including the SQUIN and Sub-session 2. We also reviewed the research information sheet and consent form together to ensure that issues of literacy would not act as barrier to women's participation. In all cases, consent forms were signed and verbal consent was recorded at the beginning of each interview. However, women were also informed of their right to stop the interview and withdraw from research at any time without having to provide a reason.

This interview approach created autonomous conditions whereby Traveller women structured the interview, determining where to begin, the topics to include/exclude, the order of events, and the amount of detail they wished to disclose (Wengraf, 2001). Follow-up questions were only asked within the parameters in which Traveller women set out in the first sub-session. Further, while recognising that research can prove beneficial or therapeutic for some interviewees (Davies and Gannon, 2006), research on sensitive subjects such as pregnancy loss can also have adverse effects, placing some participants at particular risk of distress. Acknowledging that it is unacceptable for researchers to advance research agendas at the psychological cost of participants, this study sought to mitigate causing emotional or psychological harm precisely by using the participant-led approach. Interviews were adapted to the needs of each woman, including breaks and I paid close attention to non-verbal body language. As noted in Section 5.12, I debriefed with each woman after the interview. Moreover, given that the interview was facilitated by the PHCTP, the Community Health Worker regularly engages with each woman as part of fieldwork and therefore any further issues could have been raised at that point; however, none were reported.

5.21.2 Epistemological accountability

As noted in Chapter 1, this study was underpinned by an anti-racist and feminist research practice, as such, it sought to move beyond politics of 'inclusion' to a "new politics of transparency and accountability" (Dei, 2005: 5). This includes epistemological accountability in knowledge construction and production as reflected in the choice of methodology and data analysis outlined above (Mauthner and Doucet, 2002: 139). Reflexivity is embedded in my research practice and was a core part of this study. As previously discussed, the VCR method facilitates this process through each reading, but Reading 1 in particular, prompts the researcher to locate herself alongside the participant. In doing so it, recognises the importance of "social context – material, ideological and discursive – as critical backdrops to research participants' voiced experience" (Mauthner and Doucet, 2003: 423).

Mauthner and Doucet also suggest the use of a 'research group' drawing on the insights of others (Mauthner and Doucet, 2003). These groups are somewhat analogous to 'interpretive communities' (Fish, 1980, 1989; Brown et al., 1991: 33) 'conceptual parties,' 'critical reference groups' (Miles and Huberman, 1994; Wadsworth, 1997) or BNIM interpretive analysis groups which seek to support the analysis of the cases. The group, ideally, should be as diverse as possible to enhance analysis and support the researcher's understanding of her "own internal dynamics and habits of reflection" (Froggett and Wengraf, 2004: 98). As Mauthner and Doucet (2003) note, this group provides the necessary space, context and method for operationalizing a degree of reflexivity during the analytic stages of research (418). While this study did not have such a formal mechanism for feedback, the analysis and final write-up did draw on insights provided by a number of colleagues; both Traveller and non-Travellers who reflect a range of experiences, specifically in relation to pregnancy, motherhood and loss.

I also engaged in research practice supervision with my supervisor and employment mentors in Pavee Point on a regular basis. I used these opportunities to discuss findings and analysis and asked colleagues to read drafts of my findings chapters. I feel that this approach helped to support further analysis of the research and pushed me to reflect constantly on my epistemology. This was particularly important in relation to the overall analysis and to ensure that my own assumptions were not left unchallenged, particularly by Traveller women. As previously noted, using a feminist approach to research does not always guarantee anti-racist content or ideology and therefore garnering feedback from a multiplicity of viewpoints in this regard was incredibly valuable.

5.22 Conclusion

The key research question of this study seeks to explore Traveller women's experiences of pregnancy loss in Ireland. This chapter has focused on the methodology of the study, the particular methods that were used and a rationale for their selection. It also provided a discussion on ethical considerations, specifically in relation to methodological and epistemological accountability. The next two chapters present key findings for this study; Chapter 6 presents three stories in the form of poems which were generated from detailed case studies. This approach seeks to support the reader to hear Traveller women's voices before they become mediated by the researcher and "transformed" into theory (Mauthner and Doucet, 2006). The poems are an attempt to *stay* with Traveller women (Chadwick, 2017a). Chapter 7 presents the collective findings from all interviews, in doing so it responds to the overall research question and first aim of this study which is to explore the personal, interpersonal and structural factors that mediate Traveller pregnancy loss experiences.

Chapter 6

Listening to Traveller women in a *different* way by linking micro-narratives to macro-level structures and processes: I/We/They-Poems

6.1 Introduction

Guided by the voice-centred relational (VCR) method, this study sought to explore Traveller women's experiences of pregnancy loss in Ireland on individual, interpersonal and structural levels. It aimed to link these "micro-narratives and macro-level structures and processes" (Doucet and Mauthner, 2008: 406) by *listening* to Traveller women in a *different* way (Brown, 1998: 33; Holloway, 2000). As discussed in the previous chapter, data collection and analysis are spaces which inevitably result in some voices being enhanced "while others are silenced" (Mauthner and Doucet, 2003: 423). The suppression and silencing of women's voices had been a common theme reflected in the broader childbirth literature. This is often framed in the context of 'authoritative knowledge' whereby women's embodied knowledge is actively suppressed and understood as illegitimate (see Chapter 4). It is also reflected in the broader pregnancy loss literature with women consistently reporting that their voices are not heard; they are silenced, ignored and supressed within health services.

For Traveller women, this is acutely felt as their active participation remains invisible in academic research and their needs are omitted from policy and practice, thus, masking the heterogeneity of pregnancy loss experiences and by extension Traveller women's experiences and needs. This is further compounded by the broader context in which Traveller women have been "talked about and talked at" (McDonagh, 2000: 239). This chapter attempts to address some of these gaps by placing Traveller women's *voices* on the page, both literally and figuratively speaking. Building on the work of Gilligan (1993[1982]) and Gilligan et al. (2003) and previous studies[177] where '*I'* poems were used to support the reader to hear the voices of participants, this chapter presents the *I, We* and *They* poems of three Traveller women as discussed in the previous chapter. The approach seeks to come to know the complexities and nuances within Traveller women's stories on individual, interpersonal and structural levels

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[177] See e.g.,Edwards and Weller (2012); Zambo and Zambo (2013); Woodcock (2016).

before women's accounts become mediated by the researcher and "transformed" into theory (Mauthner and Doucet, 2006; Chadwick, 2017a). The poems are an attempt to *stay* with Traveller women and in doing so, illuminate "how she speaks of herself before we speak of her" (Brown and Gilligan, 1992: 27–8). In staying with Traveller women's voices and in line with the BNIM approach, the poems are presented verbatim and chronologically rather than according to identified 'voices' by the researcher (Edwards and Weller, 2012). Therefore, breaks in the text reflect a shift in the speaker.

This chapter seeks to initiate the connection between the "cognitive and the emotional, the individual and the structural/cultural" (Mauthner, 1999: 151) by responding directly to the research question and the overall objectives. With this in mind, this chapter seeks to:

- listen to Traveller women speak about themselves before we speak of them;
- illuminate the temporal, relational and structural aspects of Traveller women's narratives; and
- demonstrate the synergetic and complimentary relationship between a BNIM influenced interviews with the VCR method.

The first poem focuses on the personal through the 'I' and the second and third poems on the 'we' and 'they' respectively. Lastly, in presenting these poems, this chapter seeks to 'stand alongside' and in solidarity with Traveller women, rather than to "gaze at them, even if only emotionally, rather than intellectually." (Edwards and Weller, 2012: 216).

6.2 I-poem, Megan

I was carrying twins
I kept getting kidney infections
I was up and down to the hospital
I was never like
I wasn't really looked about
Whenever I was bleeding or something and I would go into the hospital

I went in
I had the twins
I was treated in a way that [pause]
I mean I was only after losing me child
I went in there they told me to come out of the room and stop crying
I was only 20, 22 at the time
I didn't know
I went out in the hall and they told me to get out of the hall to stop crying
I felt that it was all building up

I was a single parent, they thought 'ah well, we'll take the child, sure you'll have no bother

I spoke to my mother about it
I says to them that I was taking the twin [pause] home with me
I brought [the baby] home

Afterwards I didn't have no aftercare

I was in labour
They left me so long that I was 10 centimetres in the pain
I actually conked out with the pain
I thought I was going to die
I had an experience that I was dying
I know this probably sounds weird but something happened when
I was conking out
I thought there was something in the room was taking me back
There was a rhyme that was saying 'you're gone, you're dead, you're gone, you're dead'
I conked out and afterwards
I had to get a caesarean then

I'll never forget that
The way I was treated
I'll tell you something, the twin was left too long
I know the twin was only 26 weeks old
I know it was, the lungs wasn't developed right
The way I was treated was wrong [emphasis] like

I went home
I kept getting infections
I didn't know what was wrong
I got stitched to hold the twins in
There was threads hanging from, you know, down below I was like 'is this right?'
I kept getting infections, infections and it was three years
I came into the women's centre
Doctor couldn't get into me womb
Me womb was still sewed up with a stitch
They left the stitches in my womb; for three years
I didn't even know

I had to go to the hospital first to get stitches cut out
I had second stage of cancer
I had to go to get the cells removed
Everything went well, but I still had to go every two years

I've never had a follow up with um, you know, 'bout how I felt about the twin dying.
I don't know what was wrong with me
I was well down and crying
I should have got some kind of support, counselling [pause] and there was never nothing
I felt was, like as a Traveller woman was that because I was different?
I was thinking too you know when the baby died I was really upset, but to put me in a room
I felt that [pause] obviously, I was depr…
I didn't know what was wrong with me

I was well down, crying all the time, couldn't eat and
I felt like, I needed [pause] some kind of support someone to come in and talk
I got nothing. Just in a room. Eat your dinner. And that was it.
I couldn't wait to get my, my mother and my father to come up to get the baby and bring it home

I don't think I got much support and all
I dunno, that was the system; they had much staff or what?
I have, that's that story

I have another story too

I was pregnant with twins again
I had a miscarriage
I went up the hospital, 'ah you're grand, the other baby's grand.'
To this day, I'd never heard anything
I never ever got no aftercare about the two
I never, never heard nothing about it

I felt that I should stop
I felt like
I'm a bad person. Stop crying.
I says 'oh God, I'm only after losing a baby' [emphasis]
I want somewhere to go [emphasis]
I thought maybe
I felt like a woman doctor telling me to stop crying. Jesus, you'd think she'd have more sense like?
I didn't want to make a big deal about it because I was a way far from home
I was on me own
I was young and I wasn't a person that would actually speak up because I was shy
I didn't want to f, like they were doctors, obviously, they knew more than I was
I was like, maybe I shouldn't cry
I thought about it and I was saying this like
I always thought -is that me?
I've done something wrong?
I think about, it's wrong.
I hadn't even time to grieve
I was out in the hall, 'get! You can't go out! [raises voice]

I'd never really thought about you know?
I was still grieving
I didn't know why it was all these things, why I was grieving
I did feel isolated
I'm a different or something?
Maybe it was because I was so upset that they thought they needed to hide me away [short pause] cause the baby died?
I'm not saying it was the doctor's fault because the baby was premature
I just felt like, did I do something wrong? To be put away?

The only time I would see someone was like when the nurses came down and the priest

He's asking me questions about down where I live and my accommodation
I felt like- are they on to me about social care or something?
Are they going to take my wee'un?
    I have a home, aye
    I'm going home to my mother and father's house

I just felt like – is he telling me something that I'm scared or should be scared of?
    I says, I wanna ring me mammy now
    As far as I know that my mother would want me to take the baby home
    I'll have to talk to me mother

I talked to my mother and my mother
    I says, mammy, I feel like they're talking to me, I feel like they're going to take my baby away or something because the way they're talking about

I was only on me own when the priest came in cause there was nobody there from home.
I felt that
I just know [raises voice]
I'm not saying that's what they were at
I felt that, that they thought I wasn't because I dunno if they knew my background or not but I felt they wanted to, they were making, they were setting things for me already
I just felt like, nah this wasn't for them
    I have to speak to me mammy first

It was 8 days after the baby died and I went in
I did come in and all
I was in and seen the baby
I wasn't well for a couple of days because I was very, very sore and sick
I have to say they were okay about me coming in and out to see [the baby]
I didn't know what to think to be honest [long pause]
I had to stay in Dublin
There was the phone call. Ding ding. I knew something was wrong.
All the same sounds I heard when I was in labour, everything came together
I had [the baby] in my arms all I did was shout for my mammy
I was shouting 'mammy!'
I just remember roaring
I'm not a person who roared and shouting, no, nothing like that.
I was just like (breathes in and out quickly) don't cry
That was even after losing your baby you didn't know what to be like

I had to go out to the waiting room to
I just went into the room
I was a wee bit upset
I shouldn't have been put in a room anyway with parents
I thought it was wrong
I was grieving
I had to leave the hallway
I didn't know where to go
I think we went through the doors or something
I think we left and went over to the room that

I just wanted to go

I was treated was treated like a dog. [Raises voice] 'you can't cry in here!'
I went 'what?' and then you stand out. 'you shouldn't be crying here!'
I'm like what's going on here, you know?
How am I posed to feel?
What am I?
How am I?
Is this like, 'you're not posed to cry!'
I'd be a strong enough person like
I would **hold (emphasis)** my grief as much as I can.
When you're after losing somebody
A baby that you thought, 'aw it's great I'm getting two twins home' which you thought alright they were
I said they were sick but you thought aw sick babies do you know prayed away as much as you can
It's like the way you say, here that was wrong like, you know.
I would never want to see another woman to be treated like that

For me, taking John home, we had brought [the baby] back in the car
I was thinking, it didn't feel real
My brother says 'where's the priest? I was just exhausted anyway after having the baby and going through a section and then the way I was treated in the hospital and then
I'm not saying it was the priest's fault cause the priest

I just felt that, aw sure it's only another burial! [*scoffs*] do you know what I mean like?
I was standing there and I couldn't speak anyway
I just thought, aw I thought he was disgusted the way the priest just lazed, dilly dallied down to the chapel and there was nothing wrong
I dunno, it just felt
I'm not saying that there was anything racist or anything
I felt really bad like in a way like this wasn't how people should be treated like that

I just felt numb
I felt weak
How did I feel? I don't know how I felt.
I felt numb
I just felt I was [..] what's wrong?

I've never […] there was never really a, a loss before. You know, belonging to me.
I might have lost my brother years ago
You keep thinking to yourself. Ach, sure I have a baby, I have a baby
At the same time, you're thinking, aw I wish [the baby] was still here

I just felt down and I didn't even know what was wrong with me
I didn't even know I was depressed
I didn't even know what was wrong like
I mean I was getting pains in me head
What is wrong with me?
Why am I getting […] why is my head so sore?

I was kind of like, there was nothing, nothing ever mentioned about it.
I went to the doctor there was never nothing mentioned
How was I mentally? How was my mental health?

I actually, I was taking painkillers.
I was taking and I didn't know
I took the whole packet of aspirin
I didn't know, it was actually an overdose that I took
I says, mammy I don't feel well
It was actually an overdose I took
I went to the hospital
I was very dainty then
I was only about 7 stone weight
I didn't, at that stage anyway
I didn't even know I was depressed
I went to the hospital they says that she, you know, I think she's depressed and why?
I was all worried 'oh mammy, what's wrong? Why am I taking all?'
I didn't even know that that what was wrong with me
I didn't even know what depression meant
You know, what was the symptoms of a depression
You'd never thought that after having a baby die, a baby die that you're going to have all these ehm, symptoms.

But I got over it!
You know people talking to you and you talking, like the way I'm talking to you
I talked about it how I felt going through
I didn't like talking about, about, when I thought I was going to die and all the rhyme.
I felt like I was going mental
I actually told people before that actually happened
I told him and he goes, 'oh my god; that did happen.' So it was proof
I was going 'am I mad?'
I never got no counselling
I never even saw a counsellor to be honest
I've never seen a counsellor
I had two
I've never had a counsellor, no counselling
I didn't know then alright
At least I know now
I've cried about it
Talked about it
I felt a bit better then when you talk

Only your family and you can trust
I'm not going to tell nobody what I done because that's embarrassment taking painkillers.
Thinking oh god, you're trying to do something
Then you're worried then if somebody thought you were going to do yourself in and you'd a child
Well they'd take the wee'in off me. That's where my worry was.
So, I didn't want anyone knowing about me taking the pain, the aspirins

I was so bad at going to the toilet. I had pain, infections
I was in pain all the time
I was like, ‘what is wrong with me?’ you know and when I went up to
I came in to him, then he says to me about, ‘oh we can’t get into your womb’
I went, ‘what?’
He took out the gut thread, it was pure green, it was black at the ends which were, I could see hanging.
How long have you got this?’ I says, well my baby’s three years. Three years ago.

I wasn’t planning any children
When I thought then, am I going to have any children now?
I need to start!
Obviously, I got pregnant like
I had to get a stitch in again later on but it was twins again
I never heard anything, to this day of it
I was only 22 years
I would know nothing about it, about how you take people up
I have no money
I says it wasn’t the fact that I wanted money, it was the fact that, I was thinking about other people
How are they going to be treated in a way, in the way that I was treated?
I said to myself, nah, if I could do something about this, but I couldn’t.
I was young
I was 22, living at home and I just got on with it.
I would never like to see anybody ever to be treated like that, you know?
I was wondering
I was 10 centimetres and the stitches still stretched and no wonder I conked out with the pain

I went for a smear
I had to get a smear test done
I’m like, right, and you’ve got stage 2.
I knew a bit about the cancer cells because of me work a wee bit
I went to Galway; they weren’t that great up there either
I turned around
I says, listen I says, they weren’t talking to me
I went oh just to let you know ehm, like, as far as I know, it’s a grade 2
Who are you, are you a nurse? I says, nah, but I like to think you’d talk to me about this.
I says, I’ve only looked up
I ask questions
I’m older now I’d like to think that I’m only asking questions
You can’t keep your mouth shut I says
As far as I’m concerned you keep your mouth shut, you get no answers.
I’m asking you now and speaking to you in a way that I have
I’m not a nurse and all or a doctor but I was told I have grade 2
Do you know what that means?
I do, I’ve cancer.

Looking at me like I was an alien
I felt little
I stood back

I know a bit about ah, medical
You know, you can look up things
You know, you can read
He must've thought that I couldn't read or write or something
He must think that I'm stupid or something
He made me feel stupid too
I'd like to think that you ask questions

I went up and ah told them I had a lot of stuff
I was in the toilet
I says, 'mammy there's something wrong'
I showed her and she gathered all the stuff that was in the toilet,
I was like what odds about miscarriage
I don't know if that's natural
I don't anybody should go through; just go on now
I never, to be honest I was, is this supposed to be natural here?
I don't think that's natural you know to go through

I did say to myself
I says maybe it's better that God made me not go through what I went through with the other baby
Me thinking about, ah it's my, it's God's will
I suppose, imagine if I had the other twin?
Imagine if I had 4 of them?
It would have been lovely to have a big family
Is there something that I done wrong?
Is it me?
Is it me?
Did I do something wrong to have these miscarriages?
I felt like I didn't do anything wrong
I've never smoked, never drunk through my pregnancies and was it something?
The way I was treated?
I never got no antenatal care
There was nothing to say that I should be doing the right things.
I had the stitch done
That I should be taking it easy or?
That's the way I felt!
I didn't know any better, I was young you see?

I just didn't know what to expect
I didn't, I just thought that this medication for medical professionals given to me these tablets
I felt was, aw, this is great now. I'm going to be alright, but there was nothing
I was getting pain all the time because the stitches throbbing
Every time you're going up to the hospital and they're looking at you as if ah, here she goes again
I made sure that I was with the second I was
Once I would bleed I was up there
I didn't care
I was trying to look after me own health like
I was trying my best

I was worried

I do a bit of screening with women
I have learned a lot about screening and about smear tests
I've always talked to most of the parents
    I remember when I got a smear test
    I remember that I got a smear test and I had second stage cancer
    I had twins and one died

When I talk about my experience, I talk to them about my losses, they open up
And you're like, have you ever talked to anybody?
When you share your own experiences
As Traveller women, we talk to each other; God you've done that and I've experienced that

I felt, God, when I had the miscarriage and I was living at home
I went home
I thought that they saw that I wasn't able to look after
You're a single parent, oh you're a Traveller, you're backgrounds Travellers
I never tell anybody my business

I probably needed someone to sit down and talk to me about
You've lost you need to talk to somebody that you can trust

If there's anybody that you can actually talk to. You can trust
You'll ever get over it
You never get over.

6.3 We-poem: Rosie

We went in for the scan the next day
We were like really shocked, and obviously crying, upset
We went into, there was like a family room
Meself and me husband had been trying for a baby for about four years, four and half years
When we found out we were pregnant, this was our dreams come true

We prayed
We prayed and we went to holy places
We went to masses, and our family prayed for us
We left it in the hands of God
We went through all the different stages, like grief, denial, until we finally reached acceptance
I don't think we ever truly accepted it
We prepared ourselves for the worst
We thought we would have had longer

We got stronger together
We supported each other
If we hadn't to be as strong, neither of us woulda gettin' through it
We had each other- like both our families were very good as well

It was us, that just kept us goin’

We were offered genetic scan
We probably knew it wasn't, because it was in the family
We went
It was in both our genes

I was on me knees, and I just felt like pushing, and I said 'this is not right'. And me husband rang me mother and father, and we went straight down to the hospital
‘We can't do it out here. I have to be brought to a ward, I have to be brought to a ward.’

The support we got was through the chaplain

That’s what we talked about, that everything was on file
We had said about having, my husband having cousins with it
We knew that there was hope as well

We didn't get to hold [the baby]
We didn't find out on the scan if it was a boy or a girl
We knew, we knew, we just kind of felt it
The actual 23 minutes, they were hell, because we didn't know what was goin’ on
We didn't know what was happenin’
We, all I seen was through the- where the room I was, just facing it was the little room
We had the few hours there with [the baby] and the next day but it was surreal

Even the night before that I [the baby], the whole head literally came out the side, and me husband was able to put his whole hand across the head. And we know that now, that was them saying goodbye.

We sat and we chatted, and she was saying how it happened to her years before. Like if ever wanted to talk, she was there.

The room we were in, it was the main maternity ward

We had, we had to arrange the funeral
We were there because they didn't want to leave us out of anything
We were involved, it's not like they just went and did their own thing
They asked us where we wanted the baby to be buried
We said 'no, it's the place we were living in’ because my family is there
We don't even go up the road
We wanted to be able to visit [the baby] whenever we wanted
We did, every day for a year

We kept gettin' told 'you don't even know; ‘you're lucky that [they weren’t] older; you'll be lucky next time’
Coming from the Traveller culture, it's a lot about our faith and religion

I know we have information comin’ out our ears, but to get it out there in a way that they know it's OK to grieve, it's OK to cry. ‘Cos this whole crap of 'men don't cry',’ that's internalising everything, and that's not gonna end well

Travellers we treat them, not as equal, but as equal standin. With the birth of a child or the death of a child, you're goin to have a good few family members
We're not goin to be picky, that's grand. But just have the respect not to turn people away

There was droves of us. We came in and it was two-by-two up the stairs, and they didn't want us there. They said 'no, no. nobody else can go up' and all this. But this to us was our last time to see this baby and say 'goodbye'; 'hello, and goodbye', basically

We are close knit, when it comes to things like this, the support is there.

6.4 They-poem: Catherine

They done an internal scan
They done a scan but they couldn't say if the wee'un was gone
Thinking they were going to do something help me stop the blood or something
They couldn't
They told me that the baby was gone
They wouldn't take me for a D and C
They couldn't do nothing for me, that the baby had to pass itself
They said to go home and I was in agony, couldn't walk

I went to the hospital again and they kept me in
They didn't tell me what was happening with my body and all
They didn't tell me what we're were going to do after, if I had to have check-ups or, they didn't
I was left in the room
They didn't even come into check me and I was sent home the next day
They didn't, they just said to me, aw you just passed the baby
They couldn't even give me pain relief
They wouldn't even say, look, well stay in and we'll observe you or what was going on
Then afterwards they didn't even
They didn't do any check-ups after
They didn't, 'aw that's just normal you can have a miscarriage'

They didn't sit down and say, 'there's a card here for support; go to your doctors in a few days;' nothing.
They didn't do nothing like and I thought it was very cruel
They said to me, there's two paracetamols, go home
I thought, 'this is a baby growing. This aint no dog. And like, they wouldn't treat a dog like that
They didn't say there's a card for support or you know, we'll have to bring you in
They did being me in for more scans and more appointments but they didn't break that down for me.

They told me the twin was gone
They were like 'you have to come back in'
They said to me, the twin will be coming away and it would probably take a long time
They would never say, there's a wee card or there's a meeting
They've got sections, if you're married, if you're young, or if you're a Traveller or you know.

They think you're a dummy
They'll treat you as a dummy

They try and tell you about your own body
But if you know what you're talking about, then they'll be like, aw, they pull the reins back again
They told me the twin died, they're like, the baby's gone, the second sac
That's just the way they were
They got different. Aw, they have different levels for different people

They gave me the anti-d injection
But you're telling them, you should know this
They didn't even tell me that
They told me that with my miscarriage, with my second pregnancy and I had to look up myself
They didn't tell me that
They should have that down on record
Just, awful. The way they treated you like
It gets upsetting when you think, they way they've treated me

I know women are supposed to have so many check-ups, but I when I had lost the twin I had more check-ups
The way they treated you. It was awful [short pause] I dunno
I wasn't the only Traveller woman they treated.

The way they're treating you. You know it's wrong.
They think, aw, sure she wouldn't understand or, do you know?
They must have thought I couldn't read or write

They confirmed that the baby was gone that night
I thought they were going to take me for a D and C but they said, no, they couldn't
Then they just gave me 2 paracetamols, I thought you cheeky dogs

When they didn't tell me, when they said, aw go home, like, they didn't tell me
They didn't break it down like that
They just said, they just said to me, well there's two set of paracetamol
They should have said to me look, rest, lie down you're going to be in pain
They are nurses with a lot of experience
They just says go home and I thought well that's like telling a newborn, new mother there's your newborn baby go home.
When I had the miscarriage, they went, 'right the baby is gone,' there's two paracetamol go home and good luck.
They didn't say, well your baby is going to pass, you're going to be in pain
They didn't explain anything to me
That's what I thought they were going to do for me, but they weren't
They were just very, 'go,' like, 'I don't have time for you'
When they said passing the baby, do you know, at that stage I was dumbfound by them
They couldn't come out with any more bad stuff
They're very naïve
They were naive because some people are naive because they don't understand something they haven't experienced

They know it all because they have seen other people go through it and people, that's wrong

They were just ignorant
I wasn't shocked by them coming out with
I just told them, go way; leave me alone
They told me I was passing the baby

They knew there was a survival of another baby
They had to keep on checking because I bled up to 4 months
They were more cautious and I think because I knew more things and I was more, maybe educated on miscarriages as I was maybe before the first time.
They kept on taking me in regularly
They were taking me more in, more often and like, checking me better
They would, they were better, maybe it was different nurses

I had was supposed to get an anti-d injection I had to say to them too
They're like, 'aw, we know that but you have to call back tomorrow.' Aw, why is it tomorrow?

There is, there is different criteria's, they put you in a section.

If you have a wee bit of reading and writing you understand what they're trying to say to you, without them trying to be patronizing while using the big words.
They do try to patronize you sometimes. They do.
They need to talk more to people and just make them feel that they are a part of a society as anybody else is

They told me that because I was a Traveller, they told me that my wee'in had to go on soy milk
They can keep it for whoever needs it, my child doesn't need to be on it
Told me that my wee'in needed it
They knew I was a Traveller
They didn't ask me, they just gave me soy milk
Not one of my wee'ins, never once did they ask me if I was a Traveller

They asked me about diabetes, heart disease and they asked me about, what else, blood pressure. Didn't ask me if I was a Traveller
They knew, they put my wee'ins on soy milk
Not once did they ask me if I was a Traveller
They didn't even say, are you a Traveller?
Yeah, they didn't even ask me if I was a Traveller
That's the way they go
No, they didn't ask
They see my mother's name, my father's name and then they assume

Not all of them are like that
You do meet some nurses and they are lovely but you do meet some nurses and they are ignorant
She was hateful to me
They tried to put her to be my midwife with my [other child]
She was very hateful. They tried to put her back in with me but I was like, nah

They’re a midwife 40 years, but not one of them has a wee’in.

6.5 Conclusion

This chapter provided a unique presentation of both the BNIM influenced interview and VCR method by inviting the reader to stand in solidarity with Traveller women and in doing so, hearing and *staying* with their voices. The poems illuminate different facets of Traveller women’s experiences on individual, interpersonal and structural levels. The next chapter presents the collective findings from all interviews and responds to the overall research question. It provides insight into the relationship between Traveller women’s individual and interpersonal experiences of pregnancy loss and the broad intersecting structures in which they are located.

Chapter 7

Traveller women's stories of pregnancy loss: abandonment, neglect, non-consent to treatment and discrimination

7.1 Introduction

This chapter seeks to reveal a 'sense of the whole story' by attending to the multiplicity of Traveller women's voices, views and perspectives through the lens of the 'common stories told.' By stories, I mean Traveller women's subjective reconstructions of their pregnancy loss experience, in their own words. This includes women's presentations of main events, protagonists, plot, subplots and key characters (Mauthner and Doucet, 2008). Narrative denotes an interpretation or analysis (meaning-making) of those stories.

Using the VCR method framework, this chapter focuses on the main plots of Traveller women's stories, how they speak and present themselves, how they speak about their relationships with others and the socio-political contexts in which they locate their experiences. As such, this chapter asks:

1. What is the overall collective narrative of pregnancy loss as told by Traveller women?
2. What are the ontological narratives?
3. What are the relational narratives?
4. What are the conceptual narratives?

This chapter is structured into two distinct sections. Sections 7.2 through 7.12 attends to the first question, that is, what is the 'collective narrative,' or 'common stories told' articulated by Traveller women? These collective stories are those which appear consistently throughout what women have identified as the three stages of the pregnancy loss experience, that is, before, during and after loss. In reflecting upon the data set as a whole (Mauthner and Doucet, 1998), it became clear that loss permeated throughout each woman's interview, this includes the loss of baby and an imagined future, loss of self-identity, loss of health and well-being, loss of bodily autonomy and loss of confidence in medical professionals. These types of losses are contained in Traveller women's broader pregnancy loss stories of trauma, grief, discrimination, anger and resilience.

As noted in the previous chapter, the VCR method is rooted in a relational ontology which recognises humans as intrinsically relational beings who are interdependent rather than independent and embedded in a complex web of intimate and larger social relations (Gilligan, 1993[1982]); Ruddick, 1989; Tronto, 1995; Mauthner and Doucet, 1998a, 1998b). It is within this context that we can locate temporal and relational aspects of Traveller women's experiences as well as her own understanding of how she fits in both interpersonal and sociocultural contexts. As Mauthner (1999) suggests, by examining Traveller women's relationships, we can begin to connect the "cognitive and the emotional, the individual and the structural/cultural" (151), all of which shape and inform the pregnancy loss experience. Therefore, Section 7.4, focuses on Traveller women's experiences in relation to others. This includes Traveller women's interpersonal relationships and support networks, in addition to the relationships within the broader community.

This chapter also examines how Traveller women locate themselves and their experiences of loss within the broader social and political context in which they live. Section 7.14, focuses on those structured power relations and dominant ideologies that have emerged in Traveller narratives. This provides a framework for understanding how Traveller women's experiences are shaped and informed structurally, linking both "micro-narratives and macro-level structures and processes" (Mauthner and Doucet, 1998a, 1998b).

7.2 Stories of loss

7.2.1 Loss of a baby and imagined future

The loss of a baby and an imagined future with that baby was deeply embedded into the stories of Traveller women. In constructing their pregnancies as a bio-social event, Traveller women looked forward to their pregnancies progressing, preparing to give birth and eventually bringing their babies home and incorporating them into their family life. Traveller woman were clear that their pregnancies were very much wanted, including those which were unplanned. Women conceptualised their pregnancy loss as meaningful in having a 'lost baby' or a 'child.' This was particularly important for women who had experienced miscarriages. In acknowledging the intense ambiguity surrounding foetal personhood, women such as Catherine, were resolute in defining their loss as that of a mother's loss of a child, noting, "I would still class them as my babies. Might not to everybody else but to me, they'd be still my babies." Eileen reiterates this by referring to her interactions with medical professionals' after her miscarriage:

> To me, I don't think, they don't class it as, they don't class it as a stillbirth, I don't know. They don't class it as a child. Even though to the mother and father and family it is like.

This was the same for women who learned that they were pregnant at the time of their miscarriage and effectively described celebrating and mourning simultaneously within a short period of time for life and the death of their baby. As Deirdre recalls:

> The time we found out, we didn't know at all. I just got these shooting pains, and we were very excited. We had all these plans - within this hour and a half I had so much plans! But then when we went up to the gynae, when things started happening, it was very, very hard and emotional on us. It was very hard on me, because - I dunno, I knew it was a baby, and it was just gone, like. And then, what made it harder was that - probably for some people they find it better, but what made it harder for me was that I didn't know.

The physical loss of a baby, alongside the symbolic loss of an imagined future and expectations for a child was described as deeply painful. The losses represent clear corporeal gaps within families, with women disclosing that they continued to fantasise about their alternative family and their future. Women described spending time visualising their children alongside other family members, particularly their siblings:

> Imagine if I had the other twin? Imagine if I had 4 of them? It would have been lovely to have a big family [Megan]
>
> I think like, imagine if I had five? Do you know what I mean? I know 5 is a lot my age but it was, aye, but it was, I always still think about them […] I always look at Chloe and say there should have been 2 twins; there should have been 2 of you. Sometimes when I am playing with her, like, when my other two babies go to school, I'm like, does she feel lonely? Does she feel that her other twin is? I don't know, maybe that's just me, do you know what I mean? Does she feel lonely? Does she feel her other twin? [Catherine]
>
> I think about it because, I've always wondered if they, if they ever lived, what would they be like? What kind of? Would it have been two boys? Two girls? A boy and a girl? When I look at my children now […] you know, I've always wondered what like would be like? You know? And how would I manage? One's big, you know what I mean? But I've always wondered what it would be like. Always always wondered. What they'd look like and what kind of a sense of humour they'd had. What kind each had? You know, I always wondered […] you can't bring back your loss. You have to let it go like. But I've always wondered. [Eileen]

These visualisations were central in memorial making practices as women were clear that they had not forgotten their babies. It is in this context that losses have become integrated into Traveller women's lives and with it, the accompaniment of grief continuing to be powerfully felt and deeply expressed. Anniversaries were described as significant and incredibly difficult periods for women as they acknowledged and memorialised the absence of their baby. In what *should* have been a celebration of their birth was now marked by mourning for their death, as Catherine reflects:

> I always think, awe, they should have been born on this date. Do you know? I should be celebrating their birthday.

Men were also included in these memorial practices with women describing their partners as co-constructing these imagined futures:

> That's nearly five years ago now. Til this day I still think about that baby, yeah. My husband too, we often have our own wee talk about that baby. Because that baby was, it was due in around a family member's birthday, if it had to go on. So it's kinda hard, when it comes to that time - it's not, we don't tell anyone, no-one knows this only me and my husband, and you now, what - if the baby had to go on, what month it would have been born in. [Deirdre]

Deirdre notes that while her family were aware of her miscarriage, they did not know her estimated due date. This was something that she and her husband only knew and reflect upon time to time. However, as Deirdre points out, this date coincides with a family member's birthday, reflecting an additional dimension to her overall experience of celebrating and mourning simultaneously.

7.2.2 Loss of self-identity

Notwithstanding the small number of women who had given birth to other children prior to their loss, for the majority of Traveller women in this study, these pregnancies were the first time they had ever been pregnant. Confirmation of pregnancy indicated a symbolic shift in their socio-cultural identity and status as a woman as they embarked on a much-desired 'rite of passage,' consolidating their role as a mother. This was the case for Rosie who describes her pregnancy as the result of a long and arduous four and half years of subfertility. When she found out she was pregnant, she recalls feeling overjoyed as, "this was our dreams come true." Rosie, like other women, described this celebratory period as blissful and one in which she willingly assumed the identity of the 'expectant mother.' However, following the death of her baby, Rosie, similar to other women, was forced to contend with an identity-in-influx. This identity is temporally located in a period where women are not their previous selves (before pregnancy), nor their future selves as imagined (after pregnancy with a live baby), but rather, somewhere in between.

At six months, Rosie had come to know her pregnancy in terms of both internal and external processes. Although she notes she had lost weight in the last few weeks of pregnancy and didn't look pregnant, she recalls having a 'bump', which her husband nicknamed. She also reflects on physically feeling and seeing the body move inside her:

> It was like it was Cristiano Ronaldo was in me belly! And all these things. And even the night before that I had the baby, the whole head literally came out the side, and me husband was able to put his whole hand across the head.

Eileen also reflects on attempting to reconcile the remaining internal/external markers of her pregnancy following loss:

> I was well gone like. You could find the bump. You could, I could see myself, the development like. You know? Because maybe it was a bit bigger than usual you know? You know? It wrecked my head to be honest, for a long time after it. I'd come home and lay in bed.

These internal/interior body spaces effectively act as markers of a 'motherhood in waiting' identity when these markers become modified or shifted somehow, as in the case of pregnancy loss, so too does this identity, as indicated by Eileen as she describes, "it wrecked my head." Rosie's identity-in-influx was solidified in interactions with her extended family members whom she describes as defining and quantifying motherhood through the amount of time spent with a child, thus dismissing her experience of motherhood, and by extension, her identity as a mother. This identity appears to exist liminally[178] for women, as they move both between both biologically and socially recognised prenatal and postnatal states. Women, such as Rosie note that pregnancy loss completely changed the sense of self, recalling "[I] literally just lost meself," going on to describe, "nothin' had affected me in my life as much as that - and it completely changed me, and it completely turned everything around […] it was a big part of who I am today, and I don't think I would be where I am or who I am without having gone through that."

7.2.3 Loss of health and well-being: physical health

Women in this study describe their pregnancy losses as having had a significant impact on their physiological, emotional and psychological health and well-being; with all three frequently interacting simultaneously. Women note that they were largely unprepared for these experiences in this regard, attributing this to a lack of communication and information provided by medical staff. According to Catherine, she was in physical agony during her miscarriage, which restricted her ability to move around or walk. She recalls that the hospital did not advise her how to manage pain or bleeding at home; consequently, she returned to the hospital, seeking medical treatment. She was given common pain medication and sent home. No follow-up appointments or after-care were provided. Catherine felt that there was a lack of communication and/or preparation of what to expect, both physiologically and physically:

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[178] This refers to a state of being "betwixt-and-between" (Van Gennep, 1960; Turner, 1987) as Traveller women move between maternal identities.

> When they didn't tell me, when they said, aw go home, like. They didn't tell me, look, you're going to pass the wee'in. We're going to take you in and do whatever we need to do to check. You know? They didn't break it down like that. They just said, they just said to me, well there's two set of paracetamol. Go home.

Catherine believes that omission of this information was negligent given their professional responsibility to provide appropriate information and guidance to patients. Comparing this incident to discharging a new mother without providing advice in relation to care for her newborn, she laments:

> You know they are nurses with a lot of experience, obviously, they would have experienced a lot of it. But they didn't, they just says 'go home' and I thought, well that's like telling a newborn, new mother there's your newborn baby go home. Not explaining to her, well look, your baby needs milk.

For some women, such as Megan, physical pain extended beyond the perinatal period. Beginning in the early months of her first pregnancy, Megan required a transvaginal cervical cerclage to help prevent her from entering early labour. Cerclages are short-term interventions which are removed later in a woman's pregnancy (at around 36/37 weeks) or at the start of preterm labour[179]. In Megan's case, she went into labour at around 26 weeks and at that time the cerclage wasn't removed. Megan provides a vivid description of her labour experience which she recalls as 'hell:'

> I was 10 centimetres in the pain and they tried their best to turn the twins, which the twins were breach and they [the staff] left. I actually conked out with the pain and I thought I was going to die […] I was 10 centimetres and the stitches still stretched and no wonder I conked out with the pain. And they're up, their hands up trying to turn the wee'ins.

Megan describes suffering from pain, cramping, infections and incontinence for three years following the loss of her baby, reflecting, "I was in pain all the time." It was only after she sought to have a coil implanted into her womb and following a cervical check that her GP discovered that the "womb [was] in threads."

7.2.4 Loss of health and well-being: emotional health

Megan also refers to her emotional well-being following her first loss, "I just felt numb and I felt weak," reasoning that this was, probably "after the section and all and after the baby and all. How did I feel? I don't know how I felt. I felt numb." The feeling of dulled emotional senses matched with heightened physical senses in terms of pain was something that the majority of women described in their pregnancy loss narratives. Terms such as 'numb,' and 'dead' were used to define how women felt following loss, while others noted they did not

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[179] See Tudur-Smith et al. (2005); Rafael et al. (2011) and Korb et al. (2017) for further discussion

have a reference point or had difficulties in describing how they felt:

> I dunno how to describe it. I was all over the place. I didn't know if I was coming or going. It didn't feel real, it's like, I knew what was happening but it didn't feel real. It was like I was numb and couldn't do anything, I couldn't sleep or eat and didn't want to see my family. [Joanne]
>
> Drained. Ehm, I don't know how I felt. I felt dead inside […] But it was just, numb. Numbness. You know? I just wasn't eating, wasn't sleeping properly. It was just, just hectic like. [Eileen]

Similar experiences were reported by the majority of women whom observed a deterioration or acceleration in their appetite, in addition to having trouble sleeping and/or carrying out day-to-day activities, as described by Molly, Eileen and Megan:

> I haven't been the same since that to be honest. I haven't been the same. I have even gained weight. I always think about it […] I still have some good days and some bad days. [Molly]
>
> It went on for weeks. I was numb. I just wasn't eating, wasn't sleeping properly. It was just hectic. It was really really bad […] It took a long time after it when I think of it. it was a long time because, it was, near two years when I think of it. all. It took a good time. [Eileen]
>
> I was well down, crying all the time, couldn't eat [Megan]

7.2.5 Loss of health and well-being: mental health

Aside from a focus on physical and emotional well-being, poor mental health, in varying degrees formed a substantial part of women's pregnancy loss stories. Over half of Traveller women in this study confirmed that they struggled with depression after their pregnancy loss and were very forthcoming about their experiences in this regard. As Molly describes, "I did take depression myself after, so I did." Eileen also shares her experience with depression:

> They [GP] put me on medication for it., Prozac and it ehm, it was grand for the first few weeks. Then one day I took it and took a fit. I literally flipped. I couldn't understand why that was and I went to the doctor and said I took the tablet yesterday and I flipped. I went mental in the house.

Eileen goes on to describe returning to her doctor who advised her that it was a normal reaction to the medication; Eileen was not happy with her GP's response and sought out alternative mental health supports. She believes that the hospital should have referred her to a counselling service following loss, or at minimum, signposted available supports. Eileen reasons that medical professionals are desensitised in this context as they see loss "every day so there's nothing to them." As she notes:

> They should have transferred me to some counselling. To take this up, give you a number, give you an address, give you something. But there's nothing. See they see it every day so there's nothing to them. [Eileen]

Similarly, Rosie describes 'cracking' and experiencing a 'mental breakdown' following the death of her baby. Both Eileen and Rosie go on to explain that it took some time to overcome these instances of perceived instability and 'come back.' For Rosie, although she believes that she has healed somewhat, she uses an analogy of an egg that has cracked to describe her experience. The egg, while still intact, remains fragmented and cannot be put back to its original state:

> Mentally, you never really heal. It's like an egg, they say when you crack an egg, like it's cracked. It's never goin to be back the same way as it was. That's what it is; you'd be there. But you're gonna have these little cracks.

Both Rosie and Eileen accessed mental health services, however, they note that the services were ineffective and instead, they relied on family members for support. According to Rosie, information provided by the counsellor wasn't 'culturally appropriate' and in the absence of a reference point, she stopped attending after one session:

> I was referred to counselling by the hospital and I went back in for one week with a counsellor in the hospital. I found I was getting more comfort from my husband and my own family. The stuff that she was saying, it wouldn't've kind of to do with me in a way, it wasn't culturally appropriate. For one, where are these support groups? How am I gonna get to them? How do you just walk in the door? I've never done this before. This is completely new. None of my family have ever done this before. But, after that, that was kind of where it ended.

Expanding on what she means by 'culturally appropriate' Rosie explains:

> I suppose, coming from the Traveller culture, it's a lot about faith and religion. Now don't get me wrong, afterwards I had war with God. I never stopped believing in him, but I had many a fight with him. To me, and to the way I was brought up, you would turn to God and help you, y'know, turn to God to give you peace in your heart, and not take away the pain, but help you grieve and help you through it. And religion is a huge part of the Traveller community. Not so much in support groups or things like that. Like, when she was talking about it, I wasn't really giving her much heed […] and then when you're in a situation where you're grieving, and then you have to go into an awkward situation of the unknown, you're not gonna do it. And she was nice about it, but it wasn't. To me, at the time it didn't seem helpful - now it could have been, it coulda' been the best thing ever, but for me, I just didn't have any knowledge of it.

Although Rosie conceded that support groups may have been useful in retrospect, it wasn't a helpful suggestion at the time. Rosie points out that she was grieving in a space that she was already feeling disconnected from. Therefore, the counsellor's suggestion that she go to another unknown space with women who weren't from her peer group and who may not understand the nuances of experience was daunting for Rosie. Rosie also points to the counsellor's lack of knowledge and/or awareness in terms of the importance of religion in Traveller culture. However, with the exception of Rosie, the rest of Traveller women in this study did not recall receiving information and/or signposting of mental health services from health providers.

> I was offered no counselling. No other support. [Deirdre]

> No, I wasn’t offered anything. It was really bad [Molly]
>
> The nurses and doctors were looking after me in another way, on the health side. I would have loved a bit of counselling or someone to talk to. [Alice]
>
> When I went to the doctor there was never nothing mentioned. How was I mentally? How was my mental health? You know? [Megan]

Ellen, for example, describes not being aware that her feelings were actually a manifestation of depression, a term in which she had not encountered before:

> I was well down and crying and I should have got some kind of support, counselling [pause] and there was never nothing […] I didn’t even know what depression meant. You know, what was the symptoms of a depression and you’d never thought that after having a baby die, a baby die that you’re going to have all these symptoms. And then it came down to depression. The doctor never even mentioned once about the loss. There was nothing, nothing ever mentioned about it.

In the absence of professional supports and services, Megan, as with other women relied heavily on her mother in this regard. Furthermore, while women describe the period immediately following loss as a particularly vulnerable time in terms of evoking mental distress, they also report that these feelings did not simply dissipate overnight, extending well beyond the perinatal period. As Rosie reflects:

> Even now, like it's, it's eight years since last month, and [pause] it's just like, I'd be strong and then, boom! It never really goes away.

Important dates (i.e. birthdays and anniversaries) in addition to familial bereavement also triggered emotions and feeling of distress, anxiety and depression.

7.2.6 Loss of bodily autonomy

The loss of bodily autonomy was something that all Traveller women experienced collectively; this takes on various meanings for each woman. For some women, this was framed in relation to the loss of autonomy over an outcome that is beyond and antithetical to their own wishes. These experiences were further compounded by the lack of certainty as to the practicalities and meanings of their pregnancy losses. However, it was also reflected in some women’s stories of non-consent to medical treatments as in the cases of Rosie, Megan and Caroline. This is further explored in Section 7.4.5

7.2.7 Loss of confidence in health services

Reflecting on their experiences, Traveller women expressed a lack of confidence in health services. While this was generally in reference to the quality of care received, as with Megan and Catherine, others such as Caroline highlight the health service's lack of capacity to provide a basic standard of care. This includes, the handling of her baby's remains. Caroline's interview revolves around her story of trying to locate the baby's remains for burial:

> I says, what did youse do with it? Did youse dump it? [raises voice] and she goes, we don't know where it is. That's what they says. They, they, it's gone. We've lost it. That's what they'd done that time, aye […] It really really maddened me when I was trying to get it sorted in the hospital about everything. The baby was meant to go to the lab and from the lab to the morgue and then that was meant to be over. You know? Even though, even they say, they told me some times that when they're so small like that, the lab, the lab and the other place. They bury it. They do the burial themselves. I was still, the parents still have to be notified. I wasn't notified of nothing

Caroline was angry that she wasn't notified about the whereabouts of her baby's remains and after numerous attempts and lack of clarity from the hospital, Caroline believed that the hospital had 'dumped' her baby. She was angry and did not want another woman to go through something similar, as she explains:

> I'm angry at the fact, to me, they dumped the baby. That's what I feel like, they dumped the baby [...] I feel angry with them for doing something like that […] I don't want them to do it again to somebody else. I don't want anyone to go through what I went through because the anger *was* there and it is *still* there and that feeling is always going to be there. I have nothing to show. I have no grave to go to. No nothing […] I'll never forgive for it.

While the majority of Traveller women in this study went on to access the same services in subsequent pregnancies, Caroline suggests that had she been pregnant again, she would not have returned to the same hospital as she could not reconcile with the way in which she and her baby were treated. As she affirms, "I would not go back to it, especially what they done to the baby. I wouldn't let them put their hands on me."

7.3 What are the ontological narratives? How do Traveller women represent themselves?

The second reading of the VCR method provides the opportunity to attend to the particular subject or narrator in the interview transcripts by focusing on how women speak about themselves and the parameters of their social world (Mauthner and Doucet, 2008). This process centres attention on the active 'I' who is telling the story in an attempt to unearth the senses of self–contrapuntal 'voices.' While some of these voices are unique to each Traveller woman, there are senses of self that are echoed across all women in this study. It is in this context that Traveller women present three distinctive intersecting voices in their pregnancy loss narratives. The VCR method of analysis reveals three voices, this includes the (1) ignored voice; (2) grieving voice; and (3) resilient voice, with women associating each voice with age, maturity, experiential knowledge and in some instances, professional knowledge.

7.3.1 Ignored voice

Traveller women in this study overwhelmingly describe not being listened to by medical professionals, leaving them feeling rejected, dismissed and ultimately ignored. This ignored voice is traced throughout each woman's narrative, lacking control and currency, particularly in institutional settings. This voice is presented as passive and constrained, located in Traveller women's younger self and naivety. While appearing throughout the three stages of the pregnancy loss experience, this voice is loudest in the first two stages of pregnancy loss; that is, before and during loss. This is most apparent in Rosie's case during labour as she describes her attempts to convey to staff that they should proceed with caution as her baby had Type II Osteogenesis imperfecta (OI) or 'brittle bones.' Type II OI is considered uniformly fatal, either prenatally or in the first weeks of life. Babies with this disorder are generally born smaller, prematurely with multiple fractures and an unstable neck,[180] leaving them susceptible internal bleeding. Therefore, it is imperative that clinicians operate with extreme care and caution. Rosie was concerned that staff carrying out adnominal palpations would unintentionally break the baby's bones:

> They were looking for the chart. Couldn't find the chart. This chart wasn't being found anywhere. The chart didn't get to them until everything was over. They were pushing my stomach in, doing this (demonstrates using her hands). I was afraid they'd hurt the baby cos brittle bones babies, they're like powder.

Rosie's attempt to convey this vital information was ignored and in the absence of Rosie's medical chart, which "wasn't being found anywhere," staff continued to carry out their examination. This was further escalated when a nurse broke her waters, despite Rosie's clear and explicit objections to do so:

> The nurse then decided that she wanted to break my waters in the emergency room. I shoved her away […]. I'd be giving out to them, saying 'don't do that', and then your one (the midwife) comes up. I'm like 'no, you can't do that'. Screaming at her, and still she did it.

Rosie again describes attempting to assert her voice in convincing staff that her child requires specialised equipment for delivery:

> I said 'you can't do this. I need to be in a ward upstairs.' I said the baby has brittle bone. **You're not listening to me** (emphasis). I can't do this. I have to wait til I'm in a ward […] They hadn't any specialist equipment, that's why I kept saying; we can't do it out here; I have to be brought to a ward; I have to be brought to a ward […] Like, I'm not a doctor or nothin', haven't got a clue about any of this. I did know that this wasn't the place, you have to go up to the ward where there's special equipment and there's all of this.

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[180] For further information see: Roughley et al., (2003); Martin and Shapiro (2007); Folkestad et al. (2016); Tournis and Dede (2018)

Rosie goes on to describe giving birth in the emergency room. Her knowledge and contributions in this space were not perceived as valid in the absence of medical information contained in her file. Most participants described similar experiences of feeling like they were not listened to, their requests dismissed and wishes not respected, specifically in terms of medical treatment. Traveller women also describe medical practitioners ignoring their embodied and experiential knowledge and privileging biomedical understandings of the body. According to Catherine:

> They try and tell you about your own body but, nah, I know my body. I know what I need. You know? I'm now at this age and have so many pregnancies to know that this is wrong.

For some Traveller women, this voice is nuanced by their position as unmarried women, as Catherine notes:

> After I had the miscarriage I had was supposed to get an anti-D injection, I had to say to them too. I said you know I'm supposed to get one of them before, during pregnancy and after pregnancy cause if I don't get it after pregnancy I might not be able to conceive wee'ins again. They're like, 'aw, we know that but you have to call back tomorrow.' Aw, why is it tomorrow? There is always tomorrow! There's never you know; we can do it now. It's always tomorrow […] There's one rule for people. You just know it when you go up there, when you're a single mother or you're a young mother, or you're a Traveller. There is, there is different criteria's, they put you in a section. You're like nah, nah, nah. You're not going to treat me different.

Catherine reasons the delay in getting her injections was a result of her identity as a young, unmarried Traveller women. However, she does not think that was the only woman that was treated this way, suggesting that there was an implicit rule in the hospital which prioritised particular women over others.

7.3.2 Grieving voice

The grieving voice is an omnipresent voice, ebbing and flowing temporally. This voice is not time-bound but it is most prominent in the period immediately following loss as remnants of women's embodied materiality of pregnancy begin to slowly dissipate and their identity as an 'expectant' mother becomes fragmented. This voice is sometimes described as being expressed loudly while other times in whispers; it is articulated in public, semi-private and intimate spaces, in waiting rooms, kitchens, hospital beds, cars, bedrooms, bathrooms and cemeteries. The voice is also not always audible as it is inscribed in women's body language in recounting their pregnancy loss stories, through tears, shrinking of the body, pauses and moments of quiet reflection.

This grieving voice also encounters opposition as it is constrained and silenced, specifically in institutional spaces. Many women recall feeling dismissed by medical staff in expressing this voice, particularly in public medical spaces as with Megan who describes ‘shouting’ after the death of her baby:

> I had [the baby] in my arms all I did was shout for my mammy. I was shouting ‘mammy!’ Aw, I just remember roaring.

Megan and her partner were requested to leave the neonatal unit and were sent to a waiting room with other families. Megan describes being “a wee bit upset” and is quickly confronted by a doctor:

> You can’t cry in here! You shouldn’t be crying here! You can’t cry in here! You shouldn’t be crying here!

This response was met with both shock and confusion as Megan continues:

> I’m like what’s going on here? How am I supposed to feel? What am I? How am I? Is this like, ‘you’re not supposed to cry?’

Megan questions whether or not this voice was appropriate in this instance as she is berated by a doctor and ordered to leave the waiting room. Reflecting on this interaction, Megan queries whether or not the doctor is correct as she describes feeling like she should stop crying. Although she acknowledges that, “it was wrong that they shouldn’t have put me in with other parents especially when I was grieving,” she also feels guilty for subjecting others to her grief, believing that she was a bad person:

> I felt that I should stop crying cause there was other people sitting there and I’m making other people upset, cause they’re like, they’re wives or something are having children and there are men there’s other people there and I’m going, I felt like, I’m a bad person. Stop crying. I never felt it. I never really, I guess I says ‘oh God, I’m only after losing a baby’ [*emphasis*]. Its only where, I want to, I want somewhere to go [*emphasis*].

In this interaction Megan defies the doctor’s expectations of what was considered a normal grieving voice, that is, quiet, momentary and restricted to private spaces. Megan’s grieving voice is rejected as it does not belong in the waiting room, a space of fear, hope, optimism and anticipation. In addition to constraint and silence, this voice is also described as being dismissed by medical staff. Women recall being told to push through their grief, and in cases where women had children, they should be thankful that to have a healthy child. However, dismissal of this voice is also evident in interactions with family members as in the case of Rosie where she describes responses of grief invalidation from extended female family members who had also experienced loss in the form of miscarriages, neonatal and infant deaths.

The response from family member was, 'you don't even know. You’re lucky that [the baby] wasn't older. You'll be lucky next time,’ however, Rosie responds, ‘I felt far from lucky.’ These comments impressed upon Rosie and she goes on to recall that she did not know if she had permission to cry for her baby’s death, leaving her feeling embarrassed during the funeral:

> And it was that kind of [pause] your grief - I actually didn't know if I was allowed cry. And I remember being at the graveyard and I remember feeling embarrassed! Cos, am I meant to cry over [the baby]. I was so [pause] gone, it was like I didn't know how to react to anything, I didn't know was I allowed to feel these feelings, was I being stupid, was everyone laughing at me because […] I didn't know. I only seen [the baby] for a second and [the baby] died, was I allowed to have all these emotions, y'know?

Rosie describes feeling angry as she, “couldn't [pause] rightly grieve […] because I didn't think I was allowed to.” The suppression of this grieving voice was present across all women’s narratives and was particularly resonant for women who did not disclose loss to extended family members. This further compounds grief as they describe feeling unable to speak about their experiences with broader social networks.

7.3.3 Resilient voice

The ignored and grieving voices are clearly juxtaposed with the resilient voice. Emerging sometime after pregnancy loss, this voice has gained more perspective and maturity following loss, informing Traveller women’s sense of self-identity. Traveller women in this context present themselves as older, wiser and better equipped to deal with pregnancy loss. This voice actively questions authoritative knowledge and what in retrospect was interpreted as abusive practices of medical professionals. According to Catherine, “I have human rights like everybody else.” This voice also takes active control in negotiating with medical practitioners in aspects of their medical treatment:

> I’m older now I’d like to think that I’m only asking questions about this because you can’t keep your mouth shut I says, as far as I’m concerned you keep your mouth shut – you get no answers. [Megan]

Women also present this voice as analogous to that of a fledging phoenix, rising from the ashes, renewed and reborn following loss. As with Rosie who recalls that she “came back stronger” after her mental breakdown. For other women, this was framed as the moral of their pregnancy loss story, using it to conclude as a *coda*. For example, according to Megan, “but I got over it! You know, with a bit of help.” This latter concept of relational resilience as Megan refers to (“with a bit of help”) featured prominently in women’s narratives as they credit their relationships with others, particularly male partners and other children in helping them become resilient and 'stronger:'

> Thank God I had a strong enough, strong husband. And we both had a strong family to help us. And that's what got me and my husband over it. 'Cos they were keepin' in him strong, and then he was comin' home makin' me strong. [Deirdre]
>
> But we got stronger together, we supported each other. I feel like if we hadn't to be as strong, neither of us woulda gettin' through it. [Rosie]

Male partners were presented as extremely supportive, with Traveller women pointing to a number of examples where their partners provided both emotional and physical support. Women interpreted these events as significantly reinforcing their relationships and bonds with their partners.

7.4 What are the relational narratives?

Recognising the relational aspects of individual's narratives, the third reading of the VCR method shifts its focus to the social networks and intimate relations of participants. In doing so, it asks the researcher to listen to the ways in which participants speak about their relationships with other people and what they see as the consequences of these relationships. In particular, this reading traces the different or multiple subjectivities associated with these relationships (Mauthner and Doucet, 2008). Upon examining the relational aspects of Traveller women's pregnancy loss narratives, there are number of identified social networks, including close and intimate relations:

- Relationships with family
    - Family as a whole
    - Mothers and sisters
    - Partners or ex-partners (boyfriends, fiancés, husbands)
- Relationships with health services
- Relationships with Traveller Community Health Workers and Primary Health Care for Travellers Projects (PHCTP)

Women present these relationships in stark contrast to each another. For instance, women describe relationships with family as caring and supportive, while presenting relationships with medical professionals as broadly careless and unsupportive. Women generally present medical professionals as homogenous in this regard, but Rosie and Deirdre refer to encounters with specific individuals who demonstrated empathy and support.

7.4.1 Familial relationships: family as a whole

In focusing on these relationships, the concept of support, or lack thereof, emerged centrally in Traveller women's narratives, with the need for support conceptualised both sensorially and emotionally. Traveller women describe having strong family networks that provided primary support during and after loss. This support varied from emotional and physical to practical and medical. For others, it was just about being physically present with them. According to Caroline, "I had very much support with them. Even when I got out of hospital. I had all of them there. So, they were very good." This was also the case for Megan who refers to her family's and some neighbours' presence at her child's funeral, as she notes, "we took [the baby] in, straight in to the chapel, all my family, brothers and sisters were all there and there was a couple of neighbours and stuff all there." Family members were identified as the first point of contact for women experiencing distress, including mental distress, as Megan recalls:

> I felt like I was going mental. Not much support through counselling or nothing. I never got no counselling. I never even saw a counsellor to be honest, just family and friends.

Molly adds to this by reflecting: "my only support was family. His family were very good and also my family were very good." This was reiterated by Deirdre as she credits her family (including her in-laws) and her husband in supporting her and 'keeping her strong.'

7.4.2 Familial relationships: mothers and sisters

Traveller women also identified the gendered nature of these supportive relationships, with female relatives, including mothers and sisters cited as providing practical, emotional, social and in some instances, medical support. This is demonstrated across all Traveller women's narratives to varying degrees. Practical support was provided in the form of childcare, as female members looked after women's other children during periods of hospitalisation, medical appointments, etc. Women also reported that when they needed a 'break' (i.e. emotionally and physically) family members would look after their children. In some instances, male partners would provide this type of support.

Medical advice and support from female family members was also described by women. For example, following her release from the hospital, Eileen reflects on the lack of information provided by medical staff particularly in relation to pain management. She notes that if it wasn't for her mother, she wouldn't have known 'what to do':

> Nothing like that and I was, as I say again, I was only very young and there was mammy on the phone to me too. I hadn't a clue. I hadn't a clue. I just went home and I took 3 to 4 showers a day and mammy says, I, I, my tummy was very sore like. She says to me take 2 paracetamols or milk or

> something and go to bed. But I was never told what to do. Never told what to do. Whatever I'd done, I done what mammy had telled me. If it wasn't for mammy I wouldn't know what to do. nothing.

In terms of emotional support, Eileen recalls that her mother experienced a similar loss and they talked frequently about their shared experiences:

> Me and mammy would have talked about it a lot, cause me and mammy went through it. God rest her soul. There is no one there now.

This intergenerational experience of pregnancy loss was described by quite a few Traveller women as they recall their pregnancy losses as catalysts in spurring disclosures from their female relatives about their losses. For Kelly, her mother and grandmother had experienced numerous pregnancy losses, in the form of miscarriages, stillbirths and neonatal deaths. Kelly's mother and grandmother were also participants in this study and they drew on Kelly's experience in their narratives, noting how hard it was for them to see her go through something similar. They also described her loss as a broader bereavement for the entire family.

Similarly, Megan's mother features prominently throughout her narrative as she is identified as a key source of support during her pregnancy losses. Megan explains that she continued to live with her mother during her first pregnancy, returning to live there for some time following the death of her baby. Her mother's absence immediately after her baby's death was something that was acutely felt by Megan as she recalls shouting for her mother, "when I had [the baby] in my arms all I did was shout for my mammy. I was shouting *mammy*!" This, despite her partner being present and accompanying her to the waiting room.

While Megan's mother was not physically present during this time, she maintained contact with Megan via phone as they spoke about the burial arrangements. She was Megan's first point of contact following an interaction with the priest who inquired about her home life and capacity to arrange a burial and take care of her live son. Megan describes this interaction as distressing as she perceived it as a veiled threat to take both babies from her. Megan reiterates the need to defer to her mother in this interaction who affirmed that Megan would take both babies home with her as previously planned. As she describes:

> I was on me own when the priest came and said they were taking the child away. They would bury [the baby]. I was a single parent they thought 'ah well, we'll take the child, sure you'll have no bother.' I spoke to my mother about it and our family is very traditional. If a child died, we would bury our own children. It doesn't matter what age it is. So I says to them that I was taking [the baby] home with me. The priest asked me
>
> > How would you feel?

> Do you live at home?
>
> He’s asking me questions about where I live and my accommodation and stuff like that. And ehm, about, about the baby, the one that lived. I felt like they were on to me about social care [work] or something. Are they going to take my wee’un? I was like,
> I have a home
> I’m going home to my mother and father’s house
> Are you sure you know you have somewhere to stay?
> There’s so much going on at home and my mother had a big family and you shouldn’t look after the child
> Who’s going to support you?
> What’s happening with the burial?
>
> I just felt like – is he telling me something that I should be scared of? I says
> I wanna ring me mammy now in a wee while
> As far as I know that my mother would want me to take the baby home.
>
> We can sort things like that
> We will take the child and do a wee sermon here and there’s a wee place out the back we can bury the child.
> I’m like
> I’ll have to talk to me mother
>
> So, when I talked to my mother and my mother said I’m *surrre* you will! You’ll be taking that child home with you.
>
> I says, mammy, I feel like they’re talking to me, I feel like they’re going to take the other baby away or something because the way they’re talking about it. I’m not saying that’s what they were at but I felt that, that they knew I was a Traveller and they were setting things for me.

Megan seeks out her mother’s advice during this period and it is in this context that she presents her mother as having an authoritative form of knowledge. Megan’s second pregnancy loss is different as her mother is actively present throughout; before, during and after. This first occurs when Megan discovers ‘stuff’ in the toilet and immediately informs her mother who gathers it in a bag and brings her to the hospital. Megan recalls her interactions with staff during this time, which she believes were both dismissive and apathetic. She describes staff notifying her that she had lost her twin and that it was dinner time, something that shocks them both. Megan’s mother stays with her for some time before she was released:

> Aye, I went up and ah told them I had a lot of stuff, my mother and all was see, I was in the toilet and I says mammy there’s something wrong. So, she came in and I showed her and she gathered all the stuff that was in the toilet, it was like, you know, the afterbirth and stuff. So, she grabbed a plastic bag and me and her went to the hospital and ehm, they took it up and put it inside and right, go on in there now and we’ll have a scan. That was grand. Ah, you’ve lost one of your babies, you’ve lost one of the twins. Ah, the other one’s grand. Right, that’s fine. Right, right, ahh, sure you’re, are you hung, it’s dinner time now [long pause] and my mother looked at me. I says, I’m not even hungry, I’m going to get sick. She goes are you alright? And she stayed with me for a good while and then I was let go [long pause].

Megan also constructs her mother as an advocate, particularly in interactions with service providers. For instance, Megan's mother accompanies her to the hospital following her miscarriage and actively questions and challenges medical staff in their treatment of her daughter. This is particular evidenced following Megan's overdose; her mother brings her to the emergency room where staff became intensely preoccupied with the welfare and well-being of her surviving twin son. Megan describes her mother as becoming incensed and directing staff to take care of her daughter:

> And where's the other baby?
> Mammy said, 'the baby's at home!
> Who's looking after the baby?
> Aw, we've we've plenty of people at home watching
> It doesn't matter about the baby! This is about Megan. This is about my daughter.

This role of advocate also resonated with Catherine as she reflects on her sister, Louise:

> She's very open-mouthed so if she thinks she's being treated wrong she'll just say to them [health staff] and sometimes I would hold back, but Louise would say, 'you say to them, you say to them.' Louise would put them straight and when she puts them straight. You're better off for it. Do you know what I mean? They [health staff] would try to use big words and our Louise would be, come back at them with big words.

Catherine presents Louise as someone who explicitly advocates on her behalf by challenging authoritative figures, while at the same time, encouraging Catherine to do the same.

7.4.3 Familial relationships: partners or ex-partners (boyfriends, fiancés, husbands)

The role of men also features prominently in women's narratives, with men identified as key sources of support, specifically in attending to Traveller women's emotional and physical needs. Again, as noted in Chapter 5, these relationships varied, with some women married to Traveller men and others in non-marital relationships with non-Traveller men. In terms of women's reflections on support provided by their partners, there was no discernible difference between Traveller and non-Traveller men. However, in Megan's case, her non-Traveller partner appears peripherally throughout her story. Where he does appear, Megan reasons that both their age and maturity meant that they were both unprepared to have children in the first instance and to deal with the grief of losing a baby. Megan's relationship with this man deteriorated shortly after her baby's death and it was not clear if he assumed a role in her other child's life.

Notwithstanding Megan's case, women construct men as reliable 'caretakers' in attending to their needs. For instance, Catherine makes reference to her partner in supporting her emotionally and physically during both pregnancy losses, as she describes her fiancé carrying her to the bathroom as she could not walk due to excruciating physical pain. She also refers to his emotional support and credits him for ‘keeping her going:’

> The only thing I think that kept me going was my fiancé and my other child. If I didn’t have them I don’t think I would be sitting here. I would have went down a very bad path […] I get to lean on him in the hardest times. I can lean on him and everything will be alright because he’s kind of there. Some people doesn’t have that. He’s brilliant was brilliant the first time and the time I lost the twin.

Rosie describes her husband as extremely supportive. In her story, Rosie’s husband is present at each appointment, including when the diagnosis was disclosed. He was also present during labour, alerting her parents to her pain and accompanied her to the hospital. He remained with her during labour and delivery and consoled her after the death of her baby:

> He was handed back to me and the doctors said 'he's gone', but he took his last breath in my arms, so. My husband, me mother was there - and he was holdin’ me.

While conveying their appreciation for the support provided by their partners, women also recognise the impact of pregnancy loss on men and their relationship with men. According to Molly, her relationship with her partner was gravely impacted by her pregnancy loss. She notes that this, in addition to another bereavement in her partner’s family, was a mitigating factor in the breakdown of their relationship as he blamed himself and became depressed:

> After that happened, he blamed himself and went into depression and all that. It didn’t help our relationship. That’s why we spilt up [Molly]

Although Molly had a new partner at the time of our interview she describes her former partner as never “having really gotten over it.” Moreover, in reflecting on her current relationship in which she has two children:

> I can’t really talk to him about it [...] I don’t really like talking about it. I do feel it every time it comes up to the anniversary. I do visit the grave and he doesn’t even know I visit the grave, ‘cause I don’t like to talk about it. So, it’s just hard. He knows about it and all but I just don’t like to talk about it with him.

Molly notes that her former partner also visits the grave as it is the same plot in which his family member is buried. This is why, she reasons, she doesn’t like to visit with her current partner as, “I’d be afraid to take my actual partner now with me, in case he’d (her former partner) be there. It’s awkward.” Although Molly does not have a relationship with her former partner, she credits him in supporting her during and after loss, ‘he was very good.’ Traveller women also referred their partner’s emotional investment in the pregnancy demonstrating strong emotional reactions following their partner’s pregnancy loss. Women used terms such as ‘hurt,’ ‘devastated’ and ‘emotional’ to desire their partner’s reactions to the loss. However, women also recalled men's *capacity* to be 'strong' during this time by hiding their feelings of grief in order to ensure that they did not further exacerbate women's distress or grief:

> My partner was hurt but he would never cry in front of me. He would do his crying somewhere else. He was more worried about me and was very supportive towards me. I get to lean on him in the hardest times. [Catherine]
>
> Emotionally he'd be strong […] it was hard on him now, because he wanted a baby, another baby. He was very emotional but he was tryin to be the strong too. He didn't wanna be down in front of me at times, because he know it'd get to me. [Deirdre]

This particular construction of masculinity as strong and stoic in the face of women, yet privately emotional was evident in all interviews. For example, Deirdre describes an interaction in the hospital immediately after her pregnancy loss where she discovered him in an 'awful state' crying: "I remember walking in one day into the toilet, and he was, absolutely in an awful state crying." Deirdre explained that she appreciated that her husband expressed emotion 'in that way.' That is, in a private space so as not to upset her. As she states, "so he'd be good not to show you his emotions, be good now to tackle them that way." Deirdre also notes that her husband was supportive in creating the space for her to talk about the loss rather than stifling conversation:

> He was good for talkin', he would, he was never the kind of person that if I wanted to talk about that miscarriage, he would sit and he'd listen. He wouldn't not answer or get up and walk away. He would sit down with me, I'd say my bit, and he would have his answer on it like. He was good for talkin' out.

In their interviews, Traveller women raised concerns about the unidirectional support provided by men, reasoning that this contributed to men's internalisation of grief as they focused their attention on their partner. Rosie believed that this contributed to her partner suppressing his grief as he could not grieve the loss of their child 'properly.' As she reflects:

> He cried and it would get to him the same, but he was so worried about me and my mental health. Until I was better, he couldn't rightly grieve.

Rosie refers to the intersectional identity of her husband in framing this experience, as a man and as a Traveller man. Alluding to the disproportionate levels of suicide amongst Traveller men and lack of spaces for Traveller men to express that grief, both within (amongst peers) the and outside the community, Rosie notes:

> You've got Traveller men there who are severely depressed and don't know why. They've blocked things out. It's still inside. Even in terms of family support, Traveller men don't talk. They want to talk to each other. I see my own brothers, they'd be lookin' at him and they'd wanna say somethin', but then they just couldn't get the words out. [Traveller] men just can't jump over that line, break down that barrier.

In addressing these concerns, Traveller women acknowledge the lack of professional support extended to men:

> There was nothin' offered for him. It's aimed at the mother. [Rosie]
>
> There was nothing for my husband, he was just as bad as me but sure, no one asked how he was or what he was feeling, if he needed support. They probably thought that it didn't affect him as much but it did. [Joanne]
>
> Whatever about me, I had my mother and sisters. He didn't have anyone and that must have been hard. [Linda]

7.4.4 Relationships with other Traveller women (CHWs) and Traveller organisations

Traveller women's relationships with professionals extend beyond clinical settings and include relationships with Traveller organisations, with some women crediting Traveller Community Health Workers (CHWs) and Traveller Primary Health Care Projects (PHCTPs) in providing peer-led support, primarily after pregnancy loss. This was described in terms of informal discussions of shared experiences and signposting of services. For Megan, this was extremely useful as sharing information and in some instances their pregnancy loss experiences was helpful in normalising the events. It also provided the necessary safe space to discuss difficult and sensitive issues such as mental health without fear of reprisal:

> That's how you talk as Travellers, as Traveller women we talk to each other. God you've done that and I've experienced that. Different, different experiences or maybe its similar and then it makes the women talk about how they go 'I wouldn't go to them people, them counsellors.' But they didn't, nobody ever said to me about, about going to counsellors. I'm like, I'm the same. Nobody ever mentioned to me should I go to a counsellor. Or if there was a counsellor, it would be 6 months down the line. You know? If somebody was really depressed. Maybe somebody needing mental health services you know sometimes if they ever take their own lives. You know? And you're go, God, well you just need to talk to the mental health service. If you're on there you might have a chance […] women don't want to get into the mental health services because they feel like, they go in there, and they've got children then they're worried about, 'oh if they think I have mental health problems, what about my wee'ins?' You know, the social services then to their mental health all goes together.

Megan raises a substantial issue echoed by other women in this study as PHCTPs work to signpost Traveller women to mainstream services, including mental health services. However, as Megan, points out, women have a genuine fear of losing their children should they seek support. This places a burden on PHCTPs as they try to effectively respond to Traveller women on the ground by providing non-directive support through signposting and encouraging women to engage with mainstream services. However, at the same time, PHCTPs also seek to encourage mainstream providers to engage with Travellers by ensuring that their service is inclusive and responsive to Traveller women's needs. Yet, there is a clear disconnect between the two. For Rosie, the PHCTP co-ordinator was a ‘big source of support’ following the death of her baby, as she explains:

> She come out to me brought me a little care package type thing, home remedies and vitamins. She said if you want me to help you to refer you on somewhere, to look into stuff. If you want me to details, I'll do that for you

Rosie also refers to the blend of both personal and professional support offered by the Community Health Workers (CHWs):

> There was support in a personal capacity from the primary health care workers, and to a degree as well on a professional one, but when you don't know something you can't provide information on it, y'know? And there would've been that boundary of 'don't talk about what you don't know'. Which was good, y'know, because it's the last thing you wanna hear, 'I know everything about it', when y'know, you don't. You know that kinda way? But yeah, I would've found them very supportive.

As Rosie points out, there were clear parameters to these relationships as CHWs were limited in their capacity to provide information about her child’s diagnosis as they are not trained health professionals.

7.4.5 Relationships with health services

The significance of health services and professionals within women’s overall experience of pregnancy and loss is not new as both patient and practitioner are intimately connected through this unanticipated event. In all three stages of the pregnancy loss experience (before, during and after), Traveller women describe medical staff as unsupportive and careless and their relationships in this regard presented as tenuous. Upon reflecting on their interactions with staff, Traveller women express anger and distress in addition to concern that other women would be subject to similar treatment.

> I felt betrayed more or less. From the doctors. That’s the truth. They let me down. They let me down like. [Eileen]
>
> I was angry when it happened like, I thought if they done it to me, they’re going to do it to somebody else. [Caroline]
>
> I wanted to go to a solicitor and bring them to court and shame them for what they did. Because the outcome could have been the same, but the treatment wouldn't have been. [Rosie]
>
> I was treated was treated like a dog […] I would never want to see another woman to be treated like that or. It doesn’t matter who they are [Megan]

Traveller women locate these relationships in an overall framework of injustice pointing to experiences of: (1) abandonment; (2) neglect; (3) non-consent to treatment; (4) and discrimination.

7.5 Abandonment

Many women also describe feeling abandoned by medical staff during their pregnancy loss, with women frequently describing this as being ‘left’ alone without any further contact from staff. This was particularly heightened for women who had been admitted to hospital for additional observation or labour/delivery. In all cases this occurred in the context of being placed in an isolated room, with very little, if any, contact from medical staff. Catherine, for example, reflects on being admitted to the hospital for observation and being left in a room by herself without any interaction with staff, “I was left in the room. They didn’t even come in to check me.”

In Megan’s case, abandonment was reported in both of her loss narratives. Megan’s first recollection of this occurs during labour where she describes being left by herself, eventually recalling passing out with the pain, Megan believed she was going to die. Reflecting on the experience, Megan suggests that this could have been routine practice:

> I actually conked out with the pain and I thought I was going to die […] they were saying I went through, even the nurses says that they put me through hell. I had to get a caesarean then. But I’ll never forget that kinda, you know, the way I was treated. You know? But maybe that’s the way that it should have been.

Megan delivered twin babies, both were alive and were rushed to a neonatal intensive care unit while Megan remained in the maternity ward. Megan’s family and partner were not present during labour or delivery as they lived a substantial distance away from the hospital. Megan describes being alone in the room with very little contact from staff. As she explains:

> It was just whenever the nurse would come in and does their, their, check and all. I remember one of the nurses says, ***‘oh my God’*** [emphasis] I didn’t even know how old you **are** [emphasis] you went through a wild hard time’ and I went, ‘ah, I know I know’ any they were like, ‘what age are you? [Emphasis] I’m like, 22. Oh my God, I thought you were far older when you were on the table cause I went through **hell [emphasis], I did like.** you know? She goes, I didn’t realize you, you are the age you are [long pause].

Megan goes on to describe that she felt isolated and ‘hidden away’ from other people. She questions whether or not the medical staff were punishing her for the baby’s death or perhaps because she was so upset:

> I did feel isolated. I felt it was, I’m a different or something or you know maybe it was because I was so upset that they thought they needed to hide me away [short pause] cause the baby died. I’m not saying it was the doctor’s fault because the baby was premature, but I just felt like, did I do something wrong? To be put away? [Mmhm] but ehm. I never, no, they only time I would see someone was like when the nurses came down and the priest.

In her second story, which takes place sometime after the death of her baby, Megan describes feeling abandoned as she is left by herself in room following a miscarriage. She asserts that she needed support, someone to come and talk to her, but this did not occur. Instead, she recalls being instructed to eat her dinner:

> I felt like, I needed [pause] some kind of support someone to come in and talk to me. I didn't, I got nothing. Just in a room. Eat your dinner. And that was it.

Caroline's story also points to abandonment as she describes nurses avoiding her during and after her miscarriage. Caroline explains that she was very down and depressed at that time, and while her family would visit during the day, the evenings were particularly difficult as she was alone. The onus, she explains was on her to seek out contact with medical staff:

> I was very down, very depressed. I had my family coming and going […] that sort of took the edge of but then I was alone at night. But all the nurses kept away unless you wanted them for something, but you *had* to go looking for them. They didn't have nobody to come and speak to you about it.

Where women were hospitalised, the rooms were described as being located within maternity units in which women recall seeing and/or hearing newborn babies. This was described as particularly distressing, with women recalling being anxious to leave the hospital as soon as possible. According to Eileen:

> I says, well, can I go home or what?
>
> Well, if you want to go home now you can or you can wait 'til tomorrow. And I says, I'll go home. So, I went home. I was still bleeding like but I still went home. I wanted to get out of it. I didn't want to stay. I wanted to get back to my bed. There's nothing they could do for me. They done enough.

This was also the case for Rosie following the death of her baby as she recalls signing herself out of the hospital as soon as she was permitted to do so. After a particularly traumatic labour and birth, Rosie was kept in the hospital for further observation. She discloses later in her interview that she and her husband requested to have their baby stay within them in the room overnight. However, the room was located on the main maternity ward and Rosie vividly remembers hearing newborns crying throughout the night which was explained as extremely frightening and distressing as she believed that it was her baby that was crying. During her interview, Rosie became noticeably upset and began to cry, and after a long pause she goes on to remark that this situation was inappropriate. However, she also notes that her experience isn't isolated as two friends experienced something similar:

> I signed myself out the next morning. I was in that night, and literally, as soon as the doctor comes around the next day […] The biggest reason, the room we were in, it was the main maternity ward,

> but it was a room at the very end. So, it was a private room off the main hall of the maternity ward. The whole night through, you could just hear newborns crying [begins to cry; long pause]
>
> It was, it was scary, because you wake up, and you think it's yours.
>
> I just thought it was very insensitive, and I would've imagined they would've had different wards in different parts of the hospital, but, I thought that was very very hard. It actually happened to two friends of mine as well. So, one of them just actually got out of hospital. This caused war, and she just left but she said 'how can you do, you want to drive me sick? You want to drive me insane. I can't do this. So that was very very hard.

7.6 Neglect

All participants in this study describe feeling neglected by medical staff during and after their pregnancy loss experience. Negligence in this context is constructed in terms of staff failing to provide adequate medical information, including home management during and after loss. Additionally, this includes the failure to provide and/or offer follow-up services such as physical examinations, counselling and bereavement services/supports. Traveller women also frame negligence in terms of health professionals' lack of action and/or a delay in medical treatment. This is juxtaposed, however, in Megan's case as medical action results in prolonged pain and serious health issues.

7.7 Failure to provide comprehensive medical information

A central theme to all Traveller women's narratives of pregnancy loss was the feeling of being unprepared and ill-equipped to deal with physiological, emotional and psychological aspects of their loss. Women frame these feelings in terms of their lack of expectations of what they were about to experience; as Molly notes, "I didn't know what to expect at all. I hadn't a clue what to expect." Again, as noted in the introduction, for many women, these pregnancies were their first and therefore they lacked a reference point. Traveller women did have expectations of the ways in which they *should* have been treated by medical professionals during this time, with these expectations falling short. This ranged from being given basic medical information on pain management and blood loss to information in relation to follow-up (i.e.) physical examinations and the signposting of counselling or bereavement supports. While the lack of information refers to both during and after loss, the needs in which women articulate these were different. For instance, women describe the need for accessible practical medical information in relation to home management (i.e. how much blood should be expected and for how long; what type of pain should be anticipated and when to (re)present to the hospital). In terms of after loss, women express the need for information in relation to 'what to do next' in terms of after-care (e.g. if a follow-up appointment was required and signposting of counselling or bereavement supports).

7.8 Information during loss

In terms of home management, Traveller women recall not being able to 'manage' as effectively as they would have liked to in the absence of clear guidance or information from health professionals. This was particularly heightened for women who describe this period as 'scary' as they were unaware of: (1) what to expect physiologically (e.g. passing of tissue), etc. and (2) what was considered 'common' in terms of bleeding and pain in the absence of a reference point. Women such as Deirdre suggest that if they had received this information from medical staff beforehand they could have managed to look after themselves:

> The miscarriage started; so, if I did had to know, beforehand, I coulda' looked after meself a wee bit better, maybe, I don't know.

This was also evident in Catherine's story as she describes her experience in the hospital during her pregnancy loss. After confirming that she was miscarrying, Catherine was admitted to the hospital for the evening and 'left in the room' without any further contact from staff. She was released the next day with pain medication and recalls that she did not receive any further information:

> They didn't tell me, when they said, aw go home, like. They didn't tell me, look, you're going to pass the wee'in. We're going to take you in and do whatever we need to do to check. You know? They didn't break it down like that. They just said, they just said to me, well there's two set of paracetamol. Go home.

Caroline's experience, however, differs and she was provided with medical information in written form, in this case a folder of information before being sent home:

> Take that home with you and read through it.' That was it. Y'know, nobody sat down and spoke to you about it. It was just, 'everything is in the folder' and hand it to you and saying, aw look at that, go home now and that will help you. That's all that was given.

Caroline discloses that she was unable to access the information in the folder as she could not read. While the folder potentially contained useful information, it was of little value to Caroline and the fact that she could not access the information left her feeling further alienated.

7.9 Information after loss

Catherine expresses further frustration in relation to the lack of information in relation to follow-up treatment. She describes this as ‘cruel’ and reasons that given her relatively young age, staff could have provided some ‘directions’ to her:

> They didn’t tell me what we’re were going to do after, if I had to have check-ups or, they didn’t. I was left in the room. They didn’t even come into check me and I was sent home the next day […] Like they didn’t sit down and say, there’s a card here for support. Go to your doctors in a few days, nothing. Nothing. Do you know what I mean? Nothing breaking it down for me. Especially at 21 like, somebody could have given me some directions to do something at 21. But naw, they didn’t. they didn’t do nothing like and I thought it was very cruel. Very very cruel. [Catherine]

This gap of knowledge and guidance in terms of ‘what to do next’ following loss was present in all women’s narratives:

> They didn’t tell me to go back to the doctor. They didn’t tell me what to do. Didn’t give me nothing, nothing. Even the hospital. I thought the hospital would have […] I’ll never forget it. One of the doctors says to me you’re miscarrying, there was nothing we could do about it. [Eileen]
>
> They don’t explain to you; they don’t explain things properly to you. Right what’s happening, what’s going to happen afterwards. [Caroline]
>
> If I had a nurse or a doctor to come in and have a private chat with me […] But sure I didn't know, how could I move on? If I had to know about services at the time […] But I didn't know. [Deirdre]

In reflecting on her experience, Eileen recalls visiting her doctor’s office a short time after her miscarriage and coming across a leaflet which although did not contain exhaustive information, it did provide some ‘knowledge’ about it:

> She didn’t even give me a leaflet on miscarriage. I as actually about, it was about 2 months after it, 3 months after it, I was at the doctor again and there were leaflets on the wall about miscarriages, I actually took one and read it myself. And there wasn’t much in it but it gave me a bit, it didn’t answer anything but it seemed to give me some knowledge about it. But she, there was nothing gave me. Didn’t give me nothing, nothing.

With the exception of Deirdre, who experienced a pregnancy loss within the past five years, no other woman recalls receiving a follow-up appointment with their doctor or any other medical professional in relation to their pregnancy loss. According to Megan, “afterwards I didn’t have no aftercare after losing the twin.”

7.10 Delay in medical treatment by health services

Delay in medical treatment also emerged as a central aspect to some Traveller women’s relationships with health providers. This was particularly evident in Rosie’s case as she presents to the emergency room during labour and was not taken in immediately to be assessed:

> A&E left me in the waiting room. I literally went down on me knees. [There were] women in the waiting room start giving out, will 'you let that girl in; bring her in ahead of us; we're grand, just let her in!' [They] wouldn't bring me in. I went to the bathroom.

Rosie describes other women's concern upon witnessing that she was not immediately taken in by the hospital. Rosie recalls dropping to her knees in the waiting area, and believing that she was going to give birth, moves into a bathroom for privacy. Some time passed before she was eventually assessed by staff after multiple requests by her mother. Similarly, Catherine, reflects on her attempts to negotiate access to care during her miscarriage.

> I went to the hospital like and that, the first night of me passing the baby and they said they couldn't do nothing for me, that the baby had to pass itself. They said to go home and I was in agony, couldn't walk. I went home but I started to be in agony. They wouldn't take me for a D&C[181]. They said the baby had to pass itself. I was in agony, couldn't walk. My fiancé had to carry me to the bathroom. They didn't tell me what was happening with my body. I lay for 3 days screaming with pain.

Catherine goes on to note that she was admitted to the hospital after (re)presenting to the hospital on multiple occasions; while she felt relieved after being admitted the hospital, she explains that she was not given any further medical treatment:

> They eventually admitted me but nobody seemed to want to help me. I couldn't walk. I couldn't do nothing for myself.

This interaction highlights the irony between Traveller women's access to a service – getting through the door of a health service on the one hand, and the actual experience or participation of Traveller women within that service. Catherine was effectively admitted to the hospital for which she believed she would receive a level of care, perhaps in the form of monitoring of her situation, dispensing of pain medication or simply having someone come in to check and see if she needed something. However, these expectations were not met, and instead, Catherine reflects on a lack of motivation of staff to help (e.g. 'nobody seemed to *want* to help'), leaving her feeling isolated and abandoned. Further, delay in medical treatment was also present in Megan's narrative as she describes experiencing complications when a cervical cerclage was left in three years post delivery. This results in years of excruciating pain and frequent doctor/hospital visits:

> I was so bad at going to the toilet. I had pain, infections. Doctors saying, God Megan, it's just not cleared up. There's you know, cramps. I was in pain all the time. I was like, 'what is wrong with me?'

---

[181] A D&C refers to dilatation and curettage; a medical procedure that ends a pregnancy by removing tissue from inside of woman's uterus.

Megan’s incontinence and pain continued for three years and it was only when she availed of a free cervical check, that the cerclage was discovered. As she explains, “he says to me, ‘oh we can’t get into your womb. Your womb is sewed up.” Megan was referred back to her GP who was shocked and angry that the cerclage was left in post delivery, describing this as neglect. As Megan explains:

> My doctor she was going mad. She says to me, they neglected you! They should have had that stitch cut out of you, I’d be surprised if you had any more children. You’ll be lucky ‘cause your womb is in threads.

While Megan was relieved that the source of her pain was diagnosed, she worried that she couldn’t have any more children given her doctor’s response. Megan was referred to consultant at a major hospital where the cervical cerclage was removed. Similar to her GP, Megan recalls the consultant’s response:

> It was pure green, it was black at the ends which were, I could see hanging. The rest was pure green. And the doctor did say, ‘oh my God! This is pure neglect! This should not, how long have you got this?’ I says, well my baby’s three years. Three years ago. He just nodded and he says, nah and he wrote to Dr. A and he says you’re not going to have any children again […] even the hospital were disgusted that way that they left the stitches inside me.

Megan’s experience is reflective of one the most disturbing aspects of neglect and delay in medical treatment, not just from the perspective of her obstetrics and gynaecological care but also in terms of general practice care. As she explains, she had been re(presenting) to her GP consistently for three years with the same issue and yet was not offered an internal examination or referred to a secondary service, suggesting to some extent, the GP was dismissive of her pain and/or reluctant to investigate further. It was only when her local PHCTP advised her that she could avail of a cervical check outside the GP’s practice, in a local community centre that the issue was identified. Similar to Catherine, this particular incident highlights the gap between equality of access to a service and equality of participation and outcomes of the service for women. While extreme, Megan’s case reflects the potential negative outcomes for Traveller women if the quality of service is not prioritised.

7.11 Non-consent to treatment

The issue of non-consent to medical treatment was evident in Traveller women’s narratives. For some women, the absence of routine patient information, not being involved in decision-making and/lack or consent for obstetric procedures was described as part of normal medical practice. Upon reflecting on these experiences women described feeling excluded, frustrated and angry as they believed they did not have any other choice but to comply. In some interviews, women disclosed that they underwent caesarean sections without consent, with some women being taken for surgery and only notified after waking up. In Eileen's case she describes being put to sleep and after waking up, she was informed that "it's done now," as she explains:

> I was put to sleep and I was very groggy when I woke up. They says that's it done now. I says, 'what?' They says, that's it done. We gave you an injection. Because I have a rare blood group, negative O, they had to give me an injection, and ehm, I still didn't even know what that was even for because I got one with the other baby but I didn't know obviously, what that was for either to be honest but then […] they says that's it done.

Eileen later discloses that the doctor performed a D&C, however, this was not something she was aware of until afterwards, as she explains:

> They took me for a D&C. But, they didn't tell me. They didn't, they just told me, they done the D&C and said I miscarried and let me out. [Eileen]

Similarly, Megan reflects on her caesarean section which was something that she did provide consent for nor was aware that it had taken place. Megan describes that after a long period of labouring by herself she became unconscious and was awakened by a nurse who inquired about her age as she was 'put through hell:'

> I actually conked out with the pain and I thought I was going to die […] they were saying I went through, even the nurses says that they put me through hell. I had to get a caesarean then. But I'll never forget that kinda, you know, the way I was treated. You know? But maybe that's the way that it should have been.
>
> I remember one of the nurses says, 'oh my *god'* [emphasis]
> I didn't even know how old you *are* [emphasis] you went through a wild hard time'
> They were like, 'what age are you? [Emphasis]
>
> I'm like, 22.
>
> Oh my god, I thought you were far older when you were on the table.

In both of these cases explicit consent (or non-consent) was not present. Even where non-consent exists in women's narratives, it is described as fruitless, with medical staff proceeding with treatment. This is clear in Rosie's case where she attempts to stop a physical examination, in this case palpation of her stomach, by pleading with staff to be careful, recalling, "I'd be giving out to them, saying 'don't do that'." The examination continues and after some time the midwife breaks Rosie's waters:

> Then she decided that she wanted to break my waters in the emergency room, and I shoved her away. I won't tell you what I said to her, but, basically I said 'the baby has brittle bone, you're not listening to me, y'know.

Later in her interview Rosie returns to this event affirming her efforts to stop the procedure, explaining, “then your one (the midwife) comes up and I'm like, ‘no, you can't do that’. Screaming at her, and still she did it.” Rosie’s experience of having her waters artificially ruptured by the midwife despite explicit refusal, clearly demonstrates the limitations of women’s agency and autonomy within maternity settings. As discussed in Chapter 2, Section 2.7, women’s consent within the context of Irish maternity care is greatly restricted by the Eighth Amendment (Article 40.3.3°) of the Constitution which is operationalised and legitimatised through the HSE National Consent Policy (2017b). Currently, a woman’s consent is not required for medical interventions during pregnancy, even if the woman deems the practices to be unsafe and/or inappropriate, as reflected in Rosie’s story.

For Rosie, the death of her baby is not bound to the actions of the staff, but rather her *experience* of this event, the birth and death of her baby, would have different, as she notes: “the outcome could have been the same, but the treatment wouldn't have been.” This was evident in other interviews as Traveller women acknowledged that while their loss could not have been prevented, their experience could have been potentially different had they have been provided with adequate support and treated with respect, dignity and compassion.

7.12 Discrimination

Most women were acutely aware of their ethnicity within medical settings, with some women indicating that they were treated differently because of their ethnicity. Women also reasoned that negative interactions and micro-aggressions displayed was due to prejudice, discrimination and racism, leaving women feeling angry, isolated and disempowered. When asked how staff were able to identify their ethnicity as different to women in the majority population, Traveller women believe that health staff ascribed ethnicity based on proxies (e.g. surname [if not married or married to a Traveller), parent’s surnames, address, accent, dress, etc.]. The rationale provided by women was that they did not recall being asked to disclose their ethnicity at any stage of their interactions with health providers; this includes their GP and/or maternity staff. As Catherine notes:

> Never asked me if I was a Traveller but obviously, they see my mother’s name, my father’s name and then they assume […]

This presumption of ethnicity, according to Catherine, resulted in a lower standard of care. She reasons that health providers have low expectations of Travellers and treat them as if they were unintelligent:

> It'd be like away sit in that corner, you sit in this corner. If they think you're a dummy and they'll treat you as a dummy. But see, when you tell them, nah, no, that's wrong, they're shocked at you. They must have thought I couldn't read or write. Just because you're using bigger words than me, I understand them big words. They think, aw, sure she wouldn't understand or, do you know? [Catherine]

Catherine argues that medical professionals segregate or divide their service into different 'criteria,' placing women into different sections based on their marital status, age and ethnicity. Recalling one particular incident in which she was overlooked by a nurse whom she believes overlooked her in favour of other non-Traveller patients:

> There's a wee waiting room and to be seen because obviously, there would be patients in that ward and like I was in, before, maybe three, maybe two or three people, but they seem to be seen before me; and my fiancé says naw, I says to my fiancé it's cause I'm Pavee. I says, its cause I'm a Traveller, he says nah. I says, I know for a fact its cause I'm a Pavee. Nah, don't be thinking that. Don't be thinking that.
>
> I just knew. Do you ever just know? Do you know what I mean? Some people are just like, they're like it's not you, it's not you. Do you know what I mean? And I was like nah, nah and they came in and she seen me […] I went into see, I went into the waiting room and the woman, the nurse, they must be on different rooms for different scanners and the nurse goes, 'how long have you been waiting here?' And I goes, aw, about 10-15 minutes. She goes, 'I've been waiting for you, she goes I've been waiting for you this morning.' But because there was a different nurse in the reception, she just threw me into that room, just whatever and it must be, she took people obviously, she'd seen before and took them on ahead. Where that nurse came in with the scanner and was like, I was waiting for you […] You just know it when you go up there, when you're a single mother or you're a young mother, or you're a Traveller. There is, there is different criteria's, they put you in a section. You're like nah, nah, nah. You're not going to treat me different.

Catherine describes defying these perceived expectations by challenging staff. Megan also alludes to low expectations in describing an interaction with a consultant whereby she informs him of her cancer diagnosis. The consultant, according to Megan, appears shocked and inquires if she is a nurse and/or if she understands what she is saying. Megan describes this as an uncomfortable interaction, leaving her feeling 'stupid' with the consultant looking her like she was 'alien:'

> He says, 'do you know what that means?' Says I do, I've […] looking at me like I was an alien.
> I stood back thinking – I know a bit about ah, medical, you know, you can look up things. You know you can read up things. He must've thought that I couldn't read or write or something because he knew my background was a Traveller. Do you know what I mean? He must think that I'm stupid or something and then he made me feel stupid too. Sure, how would you know, sure? Are you a nurse or doctor? Nah, but I did, I'd like to think that you ask questions. You know? You ask questions.

Catherine explains that service providers can take advantage of Traveller women who may not understood that the treatment and abusive behaviour exhibited by staff were inappropriate. Similar to Megan, Catherine, explains:

> It's just that you didn't know, as I said if you didn't know what you're talking about, you know, the way they're treating you. You know it's wrong. They think, aw, sure she wouldn't understand or, do you know?

She goes on to reason that her experiences of neglect, delayed treatment and abuse were due to her identity as a Traveller woman and proposes that other Traveller women were subject to similar treatment:

> But that was the way they treated you. It was awful [short pause] I dunno. And I'd say I wasn't the only Traveller woman they treated. It gets upsetting when you think, the way they've treated me. I'd say I wasn't the only Traveller woman they treated that way. [Catherine]

Some women, such as Megan, frequently questioned whether or not their ethnicity shaped and informed medical providers' negative responses; for example, she says, "I was well down and crying and I should have got some kind of support, counselling [pause] and there was never nothing [pause] so that's the way I felt was, like as a Traveller woman what that because I was different, was a Traveller, you know?" Rosie also describes an interaction with her consultant after her child's diagnosis in which the consultant inferred that the diagnosis was due to consanguinity:

> She said somethin' about cousins. Me and my husband aren't closely related [and] it just happened to be down through the generations each of us happened to get the gene. To me, it was just like 'if you'd stop marrying into each other, this wouldn't happen.'

Rosie goes on to recall a follow-up appointment with a genetic counsellor following her baby's death. While she notes that the counsellor was 'very nice', she also believes that she 'had prejudice' which was unconscious. The genetic counsellor, similar to the consultant, alluded to consanguinity in contributing to Rosie's fatal foetal diagnosis:

> To me she had prejudice, that I don't think she knew she had. And again she, kinda fed into that about cousins, and then when she found out that we weren't that closely related, then she kinda changed then. But I do think there is, they jump to conclusions before they know the facts, and I think that especially Travellers do have a high rate of infant mortality, they do have a high rate of different kinds of genetic disorders within children - be it Hurlers, Brittle bones - there's definitely a good few. Not only because they're related, but because the gene pool is so small, y'know you don't have to be first cousins.

Furthermore, these interactions were not limited to health practitioners as hospital chaplains/priests are tasked with providing patient care, often in the form of listening to patients and attending to their spiritual needs. While most women recall positive experiences with hospital chaplains in providing spiritual support, such as blessing the baby's body and praying with women and their partners. Others, such as Megan note a starkly different experience. For example, following the death of her baby, Megan describes requesting her child's remains be released so she could take the baby home for a burial. From here, the hospital informed the priest to discuss the issue with her and he began to question Megan about her accommodation and family circumstances. Megan recalls feeling frightened and threatened that her baby would be taken into care:

> He's asking me questions about where I live and my accommodation and stuff like that. And ehm, about, about the baby, the one that lived. I felt like they were on to me about social care [work] or something. Are they going to take my wee'un? I was like,
> > I have a home
> > I'm going home to my mother and father's house
>
> Are you sure you know you have somewhere to stay?
> There's so much going on at home and my mother had a big family and you shouldn't look after the child
> Who's going to support you?
> What's happening with the burial?
>
> I just felt like – is he telling me something that I should be scared of?
> I went home. I thought that they saw that I wasn't able to look after, not to say that they weren't that I wasn't able, but the way they were going on about it, aw you're a single parent, oh you're a Traveller, your backgrounds Travellers.
> I'm like, right. How do they know that?
> I never tell anybody my business.
> Cause they knew straight away that I was.
> Then it's like, aw are you able to look after your child?
> Aw, there's so many living at home.
> Oh God, you're mother has a big family.
> How are you going to look after a premature baby?
> Then they said to me that they were taking the child away to do, like to do their own.
> They would do it 'cause I was a single parent, they thought 'ah well, we'll take the child, sure you'll have no bother […]
> I'm not saying that's what they were at but I felt that, that they knew I was a Traveller and they were setting things for me.

Megan goes on to extend this analysis to her parish priest who was late to her baby's funeral. Megan describes feeling 'disgusted' by this behaviour, however, she is ambivalent to attribute this to racism or discrimination as a result of her ethnicity. She starts off with, 'I just felt' then quickly iterates that she's not 'saying there was anything racist, but it's just the way,' as she notes:

> I dunno, it just felt. I'm not saying that there was anything racist or anything, but it's just the way. It doesn't matter. The priest shouldn't treat anybody like that either. You know? He knew a baby was coming to get buried, but that's the way I felt like. I felt really bad like in a way like this wasn't how people should be treated like that.

Megan also suggests that her marital status and age potentially affected her treatment by health services and the priest in this case. Similarly, Catherine indicates that her experience of differential treatment was not reducible to her ethnicity only, but also her age and marital status, as she explains:

> It was cause the unmarried mother part and the young age. Young age, definitely young age had to do with it […] To me, that's the way I felt. The age part and the unmarried mother part. They do treat you, they definitely treat you different. [Catherine]

Catherine and Megan were the only Traveller women in this study that were unmarried at the time of their pregnancy loss, and while their experiences occurred within decades of one another, both agreed that their age and marital status negatively impacted their interactions with health services. This included feeling chastised and infantilised by health service providers.

7.13 What we can learn from positive experiences

While Traveller women generally frame their relationships with health services as negative. with medical staff presented as unsupportive and careless, there are particular incidents in women's stories in which they recall positive experiences. These experiences include staff members demonstrating respect, compassion and empathy. These exchanges occurred generally *after* loss and within the context of a maternity hospital, specifically in the cases where women were admitted to stay for a short period of time. These examples were often presented in stark contrast to Traveller women's overall stories of treatment by health services.

Rosie's story is specifically located in the emergency room where she gave birth to her baby and outlined in this chapter; her experience was extremely traumatic. Despite advising staff about her child's condition and the need to exercise extreme caution and care, Rosie discloses that she was ignored. Rosie recalls this as extremely distressing as she was concerned that the slightest movement could potentially hurt her baby and adversely impact their quality of life. In her story, Rosie reiterates that she was not listened to. This is exemplified when her waters were broken, even after explicit refusal. Rosie describes feeling angry and hurt by this experience and thus and her story centred upon these specific interactions. However, Rosie also recalls a particular nurse whom she regarded as being very kind and compassionate towards her, something of which she 'will never forget.' As Rosie recalls, Mary (the nurse) accompanied Rosie to her room following the death of her baby and sat with her during this time. Rosie explains that she was not aware that she had to deliver the placenta and it was Mary who supported her through this process. Mary sat with Rosie and disclosed her own experience of loss. She also offered to talk to Rosie at any time. As she explains:

> That nurse had been there and she had helped me then to pass it […] But she was just, like we sat and we chatted, and she was saying how it happened to her years before, like if I ever wanted to talk, she was there. She was really, really nice.

This story juxtaposes Rosie's overall narrative of distress and anger. It also demonstrates a stark contrast of her experience some mere hours before with Mary's colleagues as she recalls having considerable autonomy over the final step of her labouring process. This was something Rosie did not experience during childbirth as it was 'forced and rushed,' with Rosie feeling a lack of control over the entire process. In this recollection, Rosie regains autonomy to some degree, as she is provided the necessary privacy, time and space to deliver her placenta. In doing so, she is physically and emotionally supported by a nurse who understands, to a degree, what she is going through and the best way to support her in that instance. Rosie goes on to describe Mary as having an emotional connection to her situation, noting, "she cried herself, she broke down, and she was so supportive, and so nice, and gave me her number."

The two women in this interaction are linked by a shared experience of loss and grief. Rosie was grateful for the Mary's support during this time; specifically, she was appreciative that Mary was attentive and appeared genuinely concerned for Rosie's well-being. Rosie suggests that the kindness and empathy demonstrated by Mary was an anomaly, believing that it was simply Mary's personal response, rather than a professional one, as she reflects: "I think that was more of a personal level, rather than a professional." Rosie explains that this individualised and compassionate approach was exactly what she needed during that time. It represented an affirmation that Rosie's grief and sadness was felt by someone else; as Rosie reflects, that it was a 'heart-breaking' event deserving acknowledgement. Rosie contrasts Mary's response to that of the HSE, describing her as a 'human being' rather than simply an extension of an institution.

> It was one-to-one, it was on a personal level. You don't want that kind of standoffish, professional thing when you're going through that is so personal, and so heart-breaking, that you want to see a human being. You don't wanna see the HSE, you don't wanna see this written up narrative that people have to say, you want to hear somebody say 'I know your heart is breaking, and I feel for you'. That's what I got from her.

Aside from Mary, Rosie also credits other staff as 'good' following her baby's death as they respected her wishes to spend as much time with her baby as she wanted. As explains:

> They were very good, like they said they could leave [the baby] in the room for the night. So, [the baby] was with us for a good while, and then I asked the doctor – cause I went into shock. And I said, I said 'can you bring [the baby], out or whatever'. It's not something I regret; well I know some people have said in the past like when things have happened like that, they have regretted it. But to

> me, [the baby] was gone, y'know. [The baby] was an angel in heaven, the soul was gone. We had the few hours there with [the baby] and the next day.

Deirdre also reflects on the impact of respectful and compassionate care following her loss. In her story, she describes that staff arranged for a priest to come in and visit her after her miscarriage. Deirdre explains that the priest said a blessing and gave her some items, including a certificate of birth and a candle:

> They brought in a priest in for me, and - I 'member goin' into the wee room. And he done me a wee blessin', we, me my husband a blessin', and the wee dead baby a blessin'. And he gave me a wee birth certificate, and his wee name on it, and baby of […] us, and the date. And he gave us three memorial prayers, and a wee candle […]

Deirdre believed that this was a very considerate gesture as the priest was not obliged to come to the hospital nor were the hospital obliged to contact him. She appreciated the priest for acknowledging her loss publicly:

> I actually thought it was very nice, because it was acknowledged. Because even though […] he didn't have to come and do such a thing, it's not every hospital I know does that. And he came in that day, for me, and done that wee blessin'. So, I thought, I thought it was very respectable and I liked it because my baby was acknowledged.

This acknowledgement of Deirdre's loss was important to her as it affirmed her experience of being pregnant and losing her baby, a baby which she and husband had hoped and prayed for, for some time. The priest's actions were important for both Deirdre and her husband. Similar to Rosie, this interaction signified that Deirdre's loss was significant and worthy of acknowledgement:

> It was nice that the nurses acknowledged it, that, yes, she was pregnant; yes, she had a miscarriage; and yes, it was a baby. Yeah, even now that I think back of it, it was nice to them.

However, just as Rosie suggests, Deirdre suggests that this particular incident was unique, not to her situation specifically, but to the health service in general, as other hospitals did not appear to have a similar practice. As she explains, "that just wasn't for me, that's for every lady in that hospital who has miscarriage or stillbirth, that's what they do." It is not clear if this was official hospital policy or an informal arrangement with the local priest, but as Deirdre points out, it is something that the hospital offers to every woman regardless of the 'type' of pregnancy loss. Given its religious nature, this approach may not resonate, or be welcomed by some women engaging with the hospital, but for Deirdre, it was a respectful way to mark her loss. These *small* gestures of private and public solidarity with Traveller women after loss highlights the importance of creating the conditions in which women feel supported, cared for and their experiences of loss validated. In both instances, Rosie and Deirdre reported being treated with respect and dignity; their loss was recognised and acknowledged, and as a consequence, their experience in these instances were regarded as positive.

7.14 What are Traveller women's conceptual narratives? What are the structured power relations and dominant ideologies that frame Traveller women's narratives?

The way in which Traveller women's pregnancy loss experiences are 'lived,' informed and narrated is also contingent on the broader context in which shapes their sense of self. This includes cultural, economic, historical, political, policy and social structures (Mauthner and Doucet, 2008). Reading 4 of the VCR method seeks to understand a participant's experiences as located within these intersecting structures (Mauthner and Doucet, 1998a; Mauthner, 1999). As noted in Chapter 5, this reading is an example of what Somers (1994) describes as 'conceptual narratives' – that is, "concepts and explanations that we construct as social researchers" (620). As such, this reading seeks to, 'reconstruct and plot over time and space the ontological narratives and relationships of historical actors, the public and cultural narratives that inform their lives, and the crucial intersection of these narratives with other relevant social forces' (Somers, 1994: 620). In reviewing Traveller women's stories from the previous readings and drawing on Mauthner and Doucet (1998a, 1998b), specific attention was focused on the structural dimensions of women's stories. The immediate context for Traveller women's stories is located within obstetric settings where hierarchies of multiple forms of power coalesce leading to the normalisation of such relations (Martin, 1984, 2001a; Murphy-Lawless, 1993, 1998, 2015; Jordan, 1997; Kennedy, 2002, 2004, 2012; Davis-Floyd, 2003) The concept of power, or lack thereof, thus, emerges in the overall collective narrative of Traveller women, transpiring on a number of levels (micro, meso and macro). Traveller women in this regard are interpreted as intersectional actors situated within and against relations of power.

7.14.1 Stories of constraint

For the majority of Traveller women in this study, the negative experiences with health service providers in obstetric settings compounded the distress and trauma of the pregnancy losses. Health providers were presented as agents of control who seek to (re)assert normative relations of power through their interactions with Traveller women. On a micro level, this is demonstrated through women's articulations of micro-aggressions, as outlined above, as being dismissed, ignored, infantilised and mistreated by service providers. While on a meso level, Traveller women highlight feelings of constraint due to their lack of power in decision-making in obstetrical settings, including those of Megan and Eileen who recalled not giving consent to medical treatment or being disregarded in their explicit refusal to provide consent, as in the case of Rosie. Women describe feeling most *powerless* and unable to exercise agency as they are subject to institutional policies and procedures outside of their control. This assessment can be traced to HSE policy which is subject to the Eighth Amendment (Article 40.3.3°) of the Irish Constitution that in effect effective suspends a woman's right to bodily autonomy during pregnancy and childbirth as discussed in Chapter 2. Again, although clinicians have been using the Eighth Amendment in guiding their clinical practice since 1983, it wasn't until relatively recently that the HSE developed its official National Consent Policy which refers to the ambiguity surrounding a woman's right to refuse treatment, including procedures that she deems unsafe and inappropriate, as reflected in Rosie's story.

On a macro level, Irish maternity services have been disproportionately understaffed, underdeveloped, underfunded and subject to intense public scrutiny following a number of national scandals as outlined in Chapter 2. This has also been compounded by two economic crises in the 1980s and late 2000s, with the later crisis resulting in severe restrictions of existing public maternity services, with budgets cut by more than 20%, and further midwifery staff shortages, taking Ireland below internationally recommended ratios to maintain clinical safety (KPMG, 2009; Holohan, 2014; O'Regan, 2014; Murphy Lawless, 2015: 208). This is had a substantial impact on service provision, with medical negligence cases relating to maternity care disproportionately comprising of more than half of the pay-outs made by the State, despite maternity services making up only 3% of the HSE budget (Gallagher, 2018). According to the State Claims Agency (2015), in a four year period (2010–2014), the average medical negligence pay-out by maternity services increased by 80%,[182] almost twice that reported by other health services. This, coupled with poor working conditions, according to Murphy-Lawless, has given rise to such low morale amongst midwifery staff, that, "just getting through one's shifts, without undue jeopardy to oneself and others, can be viewed as a major accomplishment" (215). Moreover, located within a biomedical framework, maternity services have become more medicalised and hospital-based in the past 50 years, resulting in a consultant-led service (Kennedy, 2002, 2004, 2012; Murphy-Lawless, 2015) This has had particular consequences for women; in terms of:(1) midwifery and nursing staff, the majority of whom are low-paid women (Gouda et al., 2015; Medical Council of Ireland, 2016; Ní

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[182] Total transactional expenditure on Maternity services related claims has increased 80% from €32 million in the year 2010 to €58 million in 2014 (State Claims Agency, 2015).

Sheaghdha, 2018) and (2) as service users whose needs tend to be forfeited against the demands of obstetricians; the majority of whom are men (CSO 2011a; Medical Council of Ireland, 2016).

7.14.2 Normalising negative experiences

While women acknowledge that negative interactions were fundamentally wrong, not all identify their experiences as being starkly different from women in the majority population. Instead, women reason that such practices constituted an integral part of obstetric treatment, indicating that practices were sanctioned, normalised and institutionalised. The similarities across the stories presented, in addition to the key literature reviewed for this study suggests that women are correct in their assessment, with policy and legislation effectively legitimising such practices which are then normalised and sanctioned by medical professionals. For Megan, this is illustrated in her description of her labouring experience during her first pregnancy and loss. She reflects on being left by herself during this time and recalling passing out with the pain; Megan actually believed she was going to die. Reflecting on the experience, Megan recalls that, 'that's the way it should have been', suggesting this could have been routine practice:

> I actually conked out with the pain and I thought I was going to die […] they were saying I went through, even the nurses says that they put me through hell. I had to get a caesarean then. But I'll never forget that kinda, you know, the way I was treated. You know? But maybe that's the way that it should have been.

This is also the case for Caroline who described her persistence in seeking information in relation to her baby's remains, with hospital reporting that they did not have any record. After some time, the hospital finally admitted that the remains had been lost, which Caroline believes was simply a euphuism for 'dumping' her baby. Again, similar to Megan, while consciously acknowledging the reprehensibility of the hospital's actions, Caroline reasons that this was customary at *that time,* "that's what they says. They, they, it's gone. We've lost it. That's what they'd done that time." Caroline recognises that her case was not unique and that discarding remains without consent from and/or in consultation with the parent was often a routine practice of hospitals during that time (see Chapter 2, Section 2.5 for further discussion). Both Caroline and Megan locate their experiences within the parameters of what was considered 'normal.'

For other women, ethnicity, age, class, marital status was identified as determining factors in informing their interactions with service providers, e.g. women who were young and unmarried at the time of their pregnancy loss, such as Eileen and Catherine's story which differed slightly from Megan and Caroline, Catherine locates her experiences within the context of her gender and ethnicity, noting, "that was the way they treated you. It was awful [short pause] I dunno. And I'd say I wasn't the only Traveller woman they treated." Catherine's concept here of 'normal' treatment by health professionals is contingent on what was considered as acceptable behaviour in treating Traveller women.

However, Traveller women demonstrate subversion and resistance in challenging institutional and hierarchical relationships. This is clearly illustrated in both Catherine and Megan's exchanges with medical staff regarding their treatment. However, for Megan, her transgression is met with a swift sanction by her consultant who dismisses her, making her feel 'stupid,' thus, reinforcing the hierarchical control. This is also similar in Rosie's case where she informs staff of her child's diagnosis, providing clear instructions of how to carry out a physical examination. Rosie also pleads with staff to move her to a more suitable room with the necessary equipment for delivery. This was something that she discussed at length with her consultant following the diagnosis and together they developed a comprehensive birth plan for when she eventually went into labour. Rosie also actively sought further information from family members who were given a similar diagnosis and read extensively about her child's condition. Rosie brings this knowledge with her to a clinical setting and in this case, disrupts the patient/doctor role, effectively overstepping the boundary between 'expert' and 'patient' by offering an alternative treatment plan. Rosie renegotiates her role in this instance by becoming an 'informed patient' which, similar to Megan, is ultimately ignored and rejected.

7.15 What is the overall collective narrative of pregnancy loss as told by Traveller women?

The first reading of the VCR method focuses on the whole story as told by participants. In doing so, it asks the researcher to consider, 'what is happening here?' (Charmaz, 2006) by paying particular attention to central story lines in the form of recurring words, themes, events, chronology of events, protagonists, plot, subplots and key characters (Mishler, 1986; Elliott, 2005; Mauthner and Doucet, 2008). Women in this study reflect pregnancy loss experiences spanning over the course of 30 years, with the most recent pregnancy loss occurring 18 months ago. Nevertheless, women recall their experiences in vivid and emotional detail, indicating a collective story of pregnancy loss as a traumatic life event, which is incredibly painful and traumatic, and impacts on women's identity and esteem. Traveller women describe their pregnancy losses as emotionally and physically jarring experiences, something that was unexpected and which they felt gravely unprepared for in physiological, emotional and psychological terms.

In tracing the key events that significantly shape the pregnancy loss experience, Traveller women's narratives intensely focus on their relationships and interactions with others, specifically negative interactions with medical professionals during and after loss. It is within a framework of injustice that women tell a collective story of inequality and differential medical treatment, this includes (1) discrimination (2) neglect; (3) abandonment; and (4) non-consented treatment. These interactions inform Traveller women's broader pregnancy loss stories of trauma, grief, discrimination, anger and resilience.

Pregnancy loss was not understood as time-bound and the memories of their loss experience continues to stay with them until the present day. Women also continue to grieve, mourn and memorialise their pregnancy losses, albeit with varying intensities and temporalities, even decades after the event(s). It is in this context that the processes of history, memory and physiology are dynamically interconnected as Traveller women make sense of their experiences. This supports existing pregnancy loss literature which emphasises the long-term impact of loss on women, their partners and family members (Layne, 2003; Wilick, 2006; Rowlands and Lee, 2010; McNiven, 2014, 2016; Flenady et al., 2016; Heazell et al., 2016; The Lancet, 2016; Ui Dhubhgain, 2018: para 1).

7.15.1 Identified needs

This study is concerned with how Traveller women experience pregnancy loss in Ireland. Traveller women have overwhelmingly indicated that mainstream service delivery and provision have not met their needs. Moreover, for some women, these experiences in obstetric settings has resulted in what they have considered unnecessary trauma and distress extending beyond the perinatal period. With this in mind, women identify three key areas requiring attention: (1) quality and respectful treatment; (2) professional support; and (3) signposting of follow-up services.

7.15.2 Quality, respectful and dignified treatment

Perceptions of a general lack of quality and respectful treatment can be traced throughout the majority of women's narratives. Upon reflecting on these experiences, women provided alternative visions of how they *should* have been treated including a better quality of service which is predicated on mutual respect throughout all stages of the pregnancy loss experience. This means that women are listened to and not subject to discrimination; neglect; abandonment; and non-consented treatment as outlined in the previous sections. Respect was also extended in broader sense in ensuring that anti-Traveller racism, discrimination and negative stereotyping do not inform treatment of Traveller women by staff employed by the health services, including chaplaincy. Referring to her experience with the consultant and genetic counsellor in their inference that her child's diagnosis was a result of consanguinity, Rosie posits, that staff should be more, "culturally aware, not to jump to conclusions, y'know? To treat a person as a person, not as what you pre-judge them." She also acknowledges the frequent hostile response that extended family members receive when visiting the hospital, particularly during a significant event such as a birth or death, as she explains:

> Life and death, Travellers treat them, not as equal, but as equal standing. With the birth of a child or the death of a child, you're going to have a good few family members. To not look at that as a bad thing, but to look at that as respecting a family's way of life and their culture, and the fact that, being a new-born baby or a baby that died, that these family are comin' together to respect the baby and respect the parents, to respect the family. Yes, there's good and bad in everywhere, not everything is always gonna go to plan.

Rosie recognises the tension between hospital protocols and the cultural importance for Travellers to respect family members during significant events such as a birth or death, particularly the death of a child. As she explains:

> We are close knit, when it comes to things like this, the support is there. You're not gonna leave one of your own with nobody.

Rosie's suggests that family members will visit the hospital regardless of protocols, and instead of health services viewing this negatively, Traveller families should be embraced. Acknowledging the lack of space and facilities within hospitals, Rosie notes, "Travellers don't care - if that's a little church to the side and it's a big room, or there's another small church inside, we're not goin' to be picky." Rosie believes that this could potentially mitigate against tensions arising between families and health services.

7.15.3 Professional support

As reflected at all stages of Traveller women's pregnancy loss experiences, the importance of professional support was one of the key issues embedded throughout each narrative. All Traveller women in this study acknowledge that they were not prepared for their pregnancy losses. With the exception of Rosie, no woman had been provided with forewarning that she could potentially lose her baby, and therefore when this occurred, women expected a level of professional support to guide them through such a distressing experience. Women framed this in terms of both emotional and physical support. However, as Traveller women indicate, these expectations were not met, and instead, women were forced to seek out support through family members and Traveller organisations. Women describe feeling angry and disappointed in their interactions with medical staff and were sceptical about the service provider's capacity to support women during this time. Traveller were clear that other women should not be treated in a similar way and that major changes within obstetric settings were required to ensure this. This aligns with global literature on pregnancy loss and within the Irish context, recommendations set out in the AIMS Ireland study (2009a), the Portlaoise investigation (HIQA, 2015) and commitments in national policy frameworks and standards (Department of Health, 2016; HIQA, 2016; HSE, 2016a) as discussed in Chapter 2.

7.15.4 Information and signposting of follow-up services

The lack information and signposting of follow-up services was another key issue that all women agreed required immediate attention. Women noted that they did not have a reference point for their experiences and did not know what to expect emotionally and/or physically. This further compounded women's stress and trauma, particularly for women who experienced miscarriages at home, as they did not know what was considered normal and/or if, and when, they should seek further medical assistance. Moreover, the emotional and psychological impact of pregnancy loss was something that women did not expect and/or receive any information on. Traveller women were cognisant that any information provided should be clear and accessible and this includes consulting with women who cannot read. As Catherine points out:

> It is a disadvantage that they can't read or write or they don't know where they're going, or, I would spend, if I had 10 minutes, break it down, just 10 minutes with a person that did loss a wee'in. Try to explain to them […] I would say talk a wee bit more to the people that comes in and make them understand.

Similarly, Caroline notes that loss should be included in routine perinatal information provided by the hospital. Caroline reasons that having the information beforehand could potentially empower women so they could feel better prepared if they experience pregnancy loss:

> I think they should be more information out there for miscarriages, stillborns, there should be more information out there. Even when they find out when they're pregnant. I know it's a happy joyful

> time and everything. But they should be given leaflets off the pregnant, but still leaflets of that just in case […] if they, god forbid, if they ever did miscarry, well then they've kind of read up a wee bit.

Signposting of follow-up services was also highlighted as a key issue, with Traveller women recommending that bereavement and counselling services should be identified prior to discharge. As Deidre and Rosie note:

> If I had a nurse or a doctor to come in and have a private chat with me, and they could give you wee business cards or leaflets on services for women - not just for women, all of, for partners too, for your partner and the woman who's experienced miscarriage, stillbirth and after babies, after birth […] But sure I didn't know about services, how could I move on into any services? If I had to know about services at the time, well then it was all back to me, it was up to me to go to these. But I didn't know. [Deirdre]

> Like at that time, I didn't know the Traveller Counselling Service was there. Probably to have stuff like that more in view in hospitals when you see the leaflets, talk to counsellors or grievance counsellors or whatever, to have that stuff to hand, to pass on to the Traveller patients. [Rosie]

Rosie also well-being the need for health services to signpost Traveller women to targeted counselling services such as the Traveller Counselling Service as she was unaware that they existed but would have like to have availed of their services. How this would be operationalised is unclear as it would be contingent on the inclusion of an ethnic identifier in maternity data sets.

7.16 Conclusion

Traveller women's experiences of pregnancy loss in Ireland are told through stories of grief, constraint, distress, mistreatment and trauma. On a personal level, Traveller women describe an instantaneous emotional attachment and bond to their pregnancies. Women recall anticipating the progression of their pregnancies, including bringing their babies home and incorporating them into their family. All Traveller women in this study understand their pregnancy losses as a death of their child. Women construct their experiences as parental bereavements worthy of acknowledgment. These bereavements were described as significant emotional and traumatic events in women's lives, disrupting their planned and imagined futures.

With the exception of Rosie, all Traveller women described their pregnancy loss as an unanticipated event which they felt seriously unprepared for. The lack of information, particularly in relation to home management for miscarriage, was identified as a major gap in Traveller women's overall pregnancy loss experience, further compounding their distress. It is within this context that Traveller women stress the need for clear and accessible information on pregnancy loss, with consideration given to women who cannot read. Caroline further suggests that this information should be included in the overall maternity information packs that women receive from hospitals, as having information beforehand could potentially empower women so they could feel better prepared if they experience pregnancy loss.

For Traveller women in this study, pregnancy loss is incredibly painful and sad, and negative interactions with health services further compounded this experience, informing women's overall pregnancy loss narrative. It is within this context that Traveller women in this study share a story of injustice and inequality based on differential medical treatment, including individual experiences with service providers and engagement with institutions. Traveller women's stories are shaped by these experiences, including experiences of discrimination and medical neglect, feelings of abandonment by health staff during labour and loss, and recollections of non-consent to treatment. Traveller women describe feeling extremely isolated and disempowered by these experiences, which for many women, remain as unresolved and painful memories. Traveller women suggest that these interactions created the conditions for what they have deemed as profound and unnecessary distress and trauma. Overall, Traveller women did not feel supported by the health services that they engaged with during and after pregnancy loss. Instead, they received assistance support from familial and social networks, including Traveller organisations and Primary Health Care for Traveller Projects.

Some Traveller women reflected on their positive experiences with the health service and identified good practice, as in the cases of Rosie and Deirdre. This highlights the positive impact on Traveller women who feel like they have: (1) been treated with respect and dignity; (2) been provided with emotional and physical support; and (3) had their loss acknowledged. It is within this context that Traveller women identify the need for consistent care, quality of care respectful care and dignified treatment. This includes personalised professional medical support, comprehensive information and signposting of follow-up services. The next chapter discusses these findings in further detail the key literature presented in chapters, 2, 3 and 4.

Chapter 8

Developing a holistic understanding of Traveller women's experiences of pregnancy loss: racialized obstetric violence in Irish society

8.1 Introduction

This chapter discusses the findings of the research presented in Chapters 2 and 3 within the socio-cultural, historical and policy context. Chapter 3 provided the social, historical and policy context to the study and includes a chronology of the key policy developments relevant to Traveller women in Ireland. Chapter 4 provided a comprehensive review of the key literature informed by the research question and objectives of the study. This is followed a detailed discussion of the key concepts that inform the study including intersectionality, gendered racism, structural violence and obstetric violence. Chapter 6 illuminated a dimension of the individual, interpersonal and structural stories in the form of I/We/You poems. Chapter 7 presented the collective findings of the study. It explored the personal and interpersonal experiences of Traveller women, including their relationships with their partners and family, with Traveller organisations and Primary Health Care for Traveller Projects (PHCTPs) and relationships with health services.

The findings indicate that Traveller women were supported largely by their families and Traveller organisations during and after loss and, in general, did not feel supported by health services. Instead, Traveller women's narratives reflect negative experiences with health services; this includes abandonment, neglect and medical treatments that occurred without their consent and discrimination. There are some examples of positive experiences, with some women reporting that nurses, midwives and chaplains treated them with respect and dignity following their loss. However, these interactions were understood as an anomaly and contingent on a personal motivation rather than a professional obligation. The following sections provide structure to this discussion with research findings discussed in relation to each objective. The central research question of this study seeks to explore Traveller women's experience pregnancy loss in Ireland. The objectives of the research are to explore:

- personal, interpersonal and structural factors that mediate Traveller experiences of pregnancy loss; and
- the Voice Centred Relational Method and its contribution to a new understanding of Traveller women's lived experiences

It is clear from the analysis[183] that Traveller women's experiences of pregnancy loss are diverse and mediated by a number of individual, interpersonal and structural factors (see Figure 5). In the following sections, I use the lens of obstetric violence to elaborate on these factors, drawing on the key research findings with reference to the literature as reviewed in chapters 2 to 4, and through the stories told in chapters 6 and 7. The final section reflects on the methodological approach of this study, and in particular, considers the ways in which the VCR method has contributed to a new understanding of Traveller women's lived experiences.

8.2 How Traveller women experience pregnancy loss in Ireland: individual level

As discussed in chapters 1 and 3, pregnancy loss has been an omnipresent reality for Traveller women in Ireland. This is reflected in Traveller women's poor perinatal outcomes and disproportionately higher pregnancy loss rates, including an infant mortality rate almost four times the national rate. However, in a much broader sense, death is an everyday occurrence for Traveller women, with Traveller women's overall mortality three times the national rate, and a lower life expectancy rate almost 12 years less than non-Traveller women (See Appendix I). It is also reflected in Traveller suicide rates which are six times higher than the national rate – seven times higher for Traveller men and five times higher for Traveller women, respectively (AITHS Team, 2010a) leading Bridgie Casey to observe, "we've a pain on our shoulders from carrying coffins" (Casey, cited in Raleigh, 2017: para 1).

While death is an everyday reality for Travellers, so too is birth, with Traveller women representing the highest fertility rates both in Ireland and in Europe[184] (AITHS Team, 2010b; CSO, 2017). This study is firmly located in a liminal space[185] between the two, as Traveller women conceptualise and remember pregnancy losses as both the birth and death of their child. Traveller women are "effectively straddling or wavering between two worlds, neither here nor there, betwixt and between states of self," with this space framed by ambiguity and anxiety, of "no-longer and not-yet" (Carson, 2002: 180). Yet, despite their frequent occurrence, Traveller women's pregnancy losses are heterogeneous experiences. They involve different actors, spaces, emotions, sensations, temporalities and materialities (Letherby, 1993; McNiven, 2014).

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[183] See Chapter 3 for a detailed discussion on composing an analysis.

[184] According to the AITHS Team (2010b) the total fertility rate for Travellers in Ireland is 2.7. Comparably to other indigenous groups, Traveller's total fertility rate is it is higher than Australian Aboriginals but lower than New Zealand's Māori. This figure is the highest when compared to European countries average.

[185] Drawing on Van Gennep's (1960) *liminality*, this refers to a state of being "betwixt-and-between;" the threshold between life and death.

Pregnancy loss does not invoke a singular, universal 'Traveller' experience or have a uniform essence; they are contingent and shaped on women's broader social worlds, history and projected future (van der Sijpt, 2010: 1775). Yet, while each experience is unique, with particularities specific to each case, there are a number of commonalities which are traced across all Traveller women's narratives. In line with pregnancy loss scholarship[186] this study suggests that Traveller women experience pregnancy loss as a traumatic life event, eliciting intense physical and emotional pain, sadness, distress and grief. Evidence from this study suggest that women experience pregnancy loss as a traumatic event for the following two reasons: (1) Traveller women conceptualise this event as the death of their child; and (2) various barriers are encountered in engaging with health services, including the ways in which they recall being treated by health services during and after their loss sets. These experiences of self are told through stories of loss: loss of baby and an imagined future; loss of self-identity; loss of health and well-being; loss of bodily autonomy and loss of confidence in medical professionals.

8.2.1 Significance of loss to Traveller women: conceptualising pregnancy loss as the death of a child

As discussed in the previous chapter, while some Traveller women had given birth to other children prior to their pregnancy loss, most had not, and these pregnancies signified the first time they had ever been pregnant. Traveller women describe feeling 'happy,' 'delighted' and 'excited' when their pregnancy was confirmed. This was particularly true for Traveller women, such as Rosie and Eileen who disclosed they had been trying for some time to conceive. It is within this context that Traveller describe having a strong emotional attachment to their pregnancies. Traveller women were clear that their loss signified the death of their child by referring to their children as 'my baby,' 'my wee'in' and my 'child.' This loss then, is conceptualised and grieved akin to that of a family member. In doing so, they affirm their identities as mothers, making no distinction between pregnancy loss type (i.e.) miscarriage, stillbirth, neonatal death, etc. This fluid understanding of loss was particularly important for Traveller women who experienced miscarriage, as they acknowledge the discourse on constructed personhood, noting that others, including family members and health services, who may not regard or value their loss in the same way. This broadly compliments the existing

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[186] See e.g., Letherby (1993); Liamputtong (2000); Abboud and Liamputtong (2003a, 2003b); Adolfsson et al. (2004); Cecil and Leslie (1993) Cecil (1994a, 1994b, 1996); McCreight (2001, 2004, 2007, 2008); Athey and Spielvogel (2000); Simmons et al. (2006); Gold et al. (2014); McNiven (2014, 2016)

literature on pregnancy loss discourse and foetal personhood, while reflecting the particular cultural importance of children to Traveller women (Helleiner, 2000[1961]), as discussed in the literature and referred to in State policy documents in relation to Travellers.

While this maternal identity is reflected throughout Traveller women's stories, there are also particular periods of flux and loss of identity as women try to reconcile their former selves (pre-pregnancy and loss), current selves (post-loss) and imagined selves (post-pregnancy with a live baby). As well as grappling with and reconstructing their own social identities as mothers, Traveller women also (re)construct the social identities of their lost baby through an account of their pre-history, history and post-history (Layne 1999; Hockey and Draper 2005). This was reflected in linear narratives of pregnancy (e.g. Traveller women discover they are pregnant, they are overjoyed with this news, they begin to plan their baby's future, they disclose the news to their family, their family anticipates the baby's future, the pregnancy progresses and develops until it is disrupted and ends). However, as Keane (2009) and Layne (2003) highlight, constructing the personhood of the lost child continues beyond the end of the pregnancy. For example, every Traveller women in this study disclosed that they continue to memorialise their infant's death and fanaticise about an alternative future with their lost child, including visualising their children alongside family members such as siblings (Layne, 2003, 2006; McCreight, 2007). This imagining indicates that bereavements and losses are integrated into Traveller women's ongoing lives, accompanied by grief and heightened during particular periods (e.g. during anniversaries or other significant moments in their lives) (Layne, 2006a, 2006b; Ribbens McCarthy, 2006). In many ways, this reflects Traveller women's commitment to unwavering maternal love, which in all cases appear to transcend time and space (Layne, 2003: 215; Murphy, 2009). It also demonstrates Traveller women's dedication to intensive mothering despite loss, as they continue to dedicate time, energy and unconditional love to their children even after death. This ideology and seemingly naturalised role of women is reflected in the Irish Constitution, and is stitched into the very fabric of Traveller's social and culture life (see Chapter 3). It is also located within gendered racialization of Traveller women by the State as mothers, caretakers and as the 'greatest hope' to ensure better outcomes for their children through assimilation (Government of Ireland, 1963, 1983b).

8.2.2 Traveller women's personal experiences in obstetric settings

Evidence in this study suggests that Traveller women's distress and grief, while connected to the overall loss of their child, was further compounded by the ways in which they recall being treated by health services. Traveller women use words such as, ‘cruel,’ ‘horrible,’ ‘like a dog,’ to describe how they felt as a result of this treatment during and after their pregnancy loss. Some of these terms resonate with the pregnancy loss literature, but this is often framed in the context of embodied experiences of loss, particularly the physical dimensions of losing a baby and encountering ambiguous materialities (e.g. blood, tissue, etc.) and not in women’s qualitative recollections of their interactions with health services. With the exception of the AIMSI study (2009a), these terms parallel the broader literature in relation to indigenous (Browne et al., 2000) and minority ethnic women’s experiences in obstetric settings as outlined in Chapter 2, and in particular Roma women’s experiences of maternity settings in Europe (Centre for Reproductive Rights, 2017). It is within this context that Traveller women’s experiences of health services are told through stories of constraint, distress, mistreatment and trauma, all of which had a considerable impact on their overall physical, emotional and mental health. Each of these dimensions were described as intersecting and mutually reinforcing one another. As discussed in the literature review, since the 1970s, there has been a greater recognition amongst scholars that pregnancy loss signifies more than a medical event as it has a significant impact on a woman’s health, including her physical, mental and social well-being (Athey and Spielvogel, 2000; Gold et al., 2007; McCreight, 2008, Giannandrea et al., 2013; Nelson et al., 2013; Gold et al., 2014; Mulvihill and Walsh, 2014; Gold and Johnston, 2014; Gold et al., 2014).

In terms of physical health, Traveller women describe having unnecessary prolonged pain due to medical negligence and/or delays in medical care, as demonstrated in Catherine and Megan’s stories. For other women, this was framed in relation to a lack of access to medical information and/or inadequate professional support by health services. In relation to their emotional heath, Traveller women describe a number of feelings following loss, including feeling ‘numb’ and ‘dead,’ while others were unable to articulate precisely how they felt during their interviews. Many Traveller women recall this period as chaotic as they felt drained and helpless, unable to eat, sleep or carry out day-to-day activities. This is consistent with the literature as it reports common experiences such as anxiety, difficulty sleeping or irritability, feelings of fear, helplessness or horror; and re-experiencing pregnancy loss (Simmons et al., 2006). These feelings for many Traveller women did not dissipate, with over half of women in this study reporting that they had struggled with depression following loss. As noted in the previous chapter, Traveller women were forthcoming and open about these experiences, with some women disclosing serious incidents which required hospitalisation.

All Traveller women identified the need for mental health supports and signposting of services following loss. However, none of the women had heard of and/or used perinatal mental health services after their pregnancy loss or in subsequent pregnancies, despite some Traveller accessing the only two maternity hospitals in the country offering perinatal mental health services. These services are relatively new developments in Ireland and were effectively non-existent for some woman during their loss. In 2017, the HSE developed in its first model of care for *Specialist Perinatal Mental Health Services* which sets out a vision for perinatal mental health services in Ireland, including the expansion of the two maternity hospitals that provide specialist mental health services within the Republic of Ireland. Similar to the National Maternity Strategy and Standards discussed in Chapter 2, Section, 2.7, the model of care identifies the need for health professionals to ensure that assessments and interventions are 'culturally competent' and that women are able to understand and communicate effectively; in doing so, it also identifies targeted supports for 'vulnerable mothers' which include (HSE, 2017c: 24):

- Those having IVF, twins and first-time, older mothers;
- Those reflecting recent changes in the Irish demography and in particular ethnic minorities. This includes refugees who might suffer from mental health problems from their loss of traditional family supports together with post-traumatic stress following war violence and their subsequent journey to Ireland; and
- Adolescents

It is unclear how this will be operationalised in the absence of active participation, collaboration and resourcing of organisations who engage with the women identified, particularly young, migrant and ethnic minority women. Furthermore, it highlights a lack of awareness of the particular barriers facing women in this regarding including basic access to maternity services (DJE and Pavee Point, 2018) and how this will be addressed in order for women to access secondary maternity care, including the proposed perinatal mental health supports in the model of care. In the absence of adequate mental health services and bereavement supports, groups such the Miscarriage Association, a Little Lifetime Foundation (formerly ISANDS) and Féileacáin have addressed this gap for some women by using a peer-led approach. However, as women in this study indicate, these groups are not spaces in which Traveller women will engage with. This is clearly articulated by Rosie who acknowledges that her lack of engagement in these spaces was due to the absence of Traveller peers. This highlights the importance of inclusivity for organisations providing community-based supports and services.

Moreover, it is well established that pregnancy loss has a significant impact on a woman's overall mental health and well-being, with loss identified as a potential stressor for example psychological distress. This includes depression, anxiety, and in some cases, post-traumatic stress disorder with symptoms persisting over a considerable period of time[187] (Athey and Spielvogel, 2000; Giannandrea et al., 2013; Nelson et al., 2013; Gold and Johnston, 2014; Gold et al., 2014). Women who have higher rates of pregnancy loss and have a history of poor mental health face a significantly higher risk in this regard. Other risk factors include, a woman's socio-economic status, perceived social support, trauma history and absence of surviving children. The *All Ireland Traveller Health Study* (AITHS) (AITHS Team, 2010a) identifies Travellers as a 'high-risk' group in relation to poor mental health, with suicide five times higher and frequent mental distress three times higher for Traveller women when compared to women in the majority population.[188] This is further compounded by male suicide which is seven times higher than men in the majority population. While the AITHS (AITHS Team, 2010a) confirmed that mental health services were available to Travellers, participation and outcomes were poor, as services were often perceived as inadequate and substandard. Institutional, cultural, social and structural barriers were identified as key restrictions for Travellers accessing and engaging with mental health services. These include but are not limited to: (1) discrimination and racism (individual and institutional levels); (2) lack of trust with health care providers; and (3) lack of accessible and inclusive service provision (AITHS Team, 2010a; Kavanagh, 2015a).

Lack of engagement with mainstream mental health services was evident in this study, with only two Traveller women (Rosie and Eileen) disclosing that they had received mental health supports from designated services. While these services varied throughout the country during the time period in which the two women experienced loss (and still do), the geographic location in this instance did not appear to restrict access. The remaining women report seeking mental health support from GPs. This is in line with findings from the AITHS (AITHS Team, 2010a)

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[187] While this varies from each individual, a longitudinal study of over 13,000 women in the United Kingdom conducted by Blackmore et al. (2011) found that women who had experienced previous pregnancy losses experienced persistent depressive and anxiety symptoms after 33 months. Previous research by research conducted by Beutel et al. (1995) also found that depression following miscarriage persisted for up to 1 year.

[188] According to the AITHS Team (2010a), 62.7% of Traveller women disclosed that their mental health was not good for one or more days in the last 30 days, this was compared to 19.9% of GMS female cardholders.

as GPs were more likely than any other health service to engage with Travellers, providing frontline services and offering care for minor and more serious conditions (153). It is also important to note that the women reported regular engagement with their local Traveller organisations and Primary Health Care for Traveller Projects (PHCTPs). However, both Rosie and Eileen reflected on the parameters in which PHCTPs and Traveller Community Health Workers (CHWs) operate as they are not trained medical professionals and cannot act as a substitute for mainstream health services.

Traveller women's identity as mothers was identified as a key barrier for women seeking further mental health support beyond primary care, as women disclosed they feared that their children would be removed from the home. This is something that is reflected in the literature (Brown and Bacigalupo, 2006), and in particular, emerging work on women during the perinatal period. In the UK for instance, over one quarter of women surveyed[189] disclosed their concerns about seeking medical support as they thought their baby might be taken away (Boots Family Trust Alliance, 2013). However, Higgins (2016) et al. note that this was not the case for all women in their research in Ireland. The authors recognise the impact on child protection legislation as a mitigating factor in the reluctance of women to engage with mental health services. This places a significant responsibility on all health professionals to identify children at risk (Department of Children and Youth Affairs, 2017[2009]). However, while this highlights the gendered nature of women in this context, this study suggests that it also reflects a racial component given the historical experience of Traveller women's children being taken into institutional care (Gmelch, 1985; Helleiner, 2000[1961]). It is also reflected in Traveller's historical relationship with social workers (Fay and Crowley, 1989; O'Connell, 1996) and the overrepresentation of Traveller children in the care system[190] has informed Traveller women's apprehension of engaging with services. The evidence from this study suggests that Traveller women's intersectional identities in this case, restricts access to essential health services.

Additionally, Traveller women expressed concerns about their GPs tendency to prescribe antidepressants as in the case of Eileen who, after taking an anti-depressant for a while, 'flipped' and went 'mental in the house.' Eileen returned to her doctor and was advised that her experience could be a side-effect of the medication. Upon hearing this, she immediately

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[189] This is based on a sample size of 1,500 women.

[190] According to Coulter (2015) a disproportionate number of families before the child protection courts had at least one parent from a minority ethnic minority group. Travellers accounted for 4.4% of these cases and this was considered an under-estimation .

disposed of the tablets and disengaged from her GP in relation to mental health and sought alternative mental health supports. It is not clear if Eileen's doctor had provided information (written or otherwise) regarding the side effects of taking an anti-depressant, however, as previously noted, given poor educational outcomes, Traveller women's literacy rate remains substantially lower than women in the majority population (AITHS Team, 2010a; CSO, 2017). This is particularly important as it relates to health, with half of Travellers disclosing that they had difficulty reading instructions provided on prescription medicines (AITHS Team, 2010a: 48). This reflects Travellers' poor functional literacy and represents a significant issue for health services in ensuring the Travellers understand how to take medication accordingly. Literacy was an issue raised by most women, particularly in relation to the provision of information provided and need for clear, accessible information from health services. This aligns with recommendations from the AIMSI (2009a: 13) and national standards as discussed in Chapter 2, Section 2.7 (HIQA, 2016; HSE, 2016a).

Moreover, the concerns raised by Traveller women in relation to over-prescribing are not without merit as research suggests the misuse of and/or over prescribing medication, specifically benzodiazepines to Travellers (Cafferty and Collins, 2011). In the absence of robust data disaggregated on the basis of ethnicity, it is unclear if this is the case at a primary care level (Kavanagh, 2016; Pavee Point, 2018). However, analysis of disaggregated data[191] from the National Drug Treatment Reporting System (NDTRS) showed that a higher proportion[192] of Traveller cases were treated for benzodiazepines as a main problem drug compared with the general population from 2007 to 2010 (Carew et al., 2013).

8.3 How Traveller women experience pregnancy loss in Ireland: interpersonal level

While Traveller women's narrative reflects the ways in which they experience pregnancy loss on an individual level, these experiences are also interpersonal, involving social actors participating in and shaping women's experiences. Traveller women identify three types of relationships which mediate their pregnancy loss experiences. This includes intimate relationships (i.e. relationships with partners and family); relationships with other Traveller women (i.e. CHWs) and Traveller organisations; and institutional relationships (i.e. institutional actors and health services). Traveller women present these relationships in a

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[191] Following requests from Pavee Point, in 2007 the NDTRS implemented an ethnic question into its administrative data sets providing baseline data on Travellers accessing addiction services (Kavanagh, 2016).

[192] According to Carew et al. (2013), this was 3.2% versus 1.7%, respectively.

dichotomous manner; institutional relationships are presented as uncaring and unsupportive, while intimate and in-between relationships are caring and supportive.

8.3.1 Intimate relationships: mothers and sisters

According to the literature, grief and distress is compounded not only by the actual events of pregnancy losses but also by socio-cultural responses to loss. This includes social responses of trivialisation (Letherby, 1999) and a cultural response of silence or denigration which can lead to emotional suppression. As discussed in Chapter 2, social and cultural networks can often underestimate the impact of pregnancy loss, particularly in the case of miscarriage. This is compounded by the absence of a physical or emotional connection to the baby or awareness that the woman was pregnant in the first place. As the literature notes, these responses can result in social isolation which has a considerable impact on women's immediate and long-term health, both physical and mental as discussed in Chapter 2 (Layne, 2003; Gold et al., 2014). Notwithstanding a particular incident in which Rosie describes female extended family members dismissing, or 'policing' (Walter 1999; Small and Hockey, 2001; Hockey et al., 2001) her grief, women in this study identify other Traveller women, specifically mothers and sisters, as key actors in providing support before, during and after loss. This support is in the form of medical, practical and emotional support. Mothers were Traveller women's first point of contact before pregnancy loss, specifically in relation to the physicality of loss (e.g. unexpected bleeding or encounters with bodily fluids and materials). For most Traveller women, their pregnancy loss was their first ever pregnancy and therefore they describe not knowing what to expect and/or what was considered 'normal.' Consequently, Traveller women regarded their mothers and sisters as lay health experts with valuable experiential knowledge of pregnancy and childbirth.

While this finding parallels broader feminist scholarship in relation to the demarcation of male and female roles during pregnancy and childbirth (Longhurst, 2012), it is important to acknowledge the broader context in which Traveller women seek information from their mothers, including low levels of trust of health services. This is demonstrated in the AITHS which found that only 41% of Travellers had a complete level of trust in health professionals; this compares with a trust level of 82% by the general population. Again, this is coupled with 66.7% of service providers acknowledging that Travellers experience discrimination when accessing health services (see Chapter 3). Further, it is also in the broader context of Traveller women's higher rates of pregnancy loss and the potential that a woman's mother had a similar experience as shown by a number of women in this study. Intergenerational loss provided an additional layer to women's relationships as they discussed and shared experiences with their mothers, and in some cases, sisters. Intergenerational pregnancy loss has received very little scholarly attention from social scientists. However, given the high rates of pregnancy loss amongst Traveller women, it certainly merits further consideration.

Traveller women also describe their mothers as assuming strong advocate roles on behalf of their health care, particularly in their interactions with service providers. Similar to the ways in which Traveller women reflect maternal love and intensive mothering following the loss of their children, Traveller women's own mothers reflect this in their interactions with their daughters. The prominence of Traveller's own mothers in their lives underscores women's positive social capital gain (Bourdieu 1977, 1984), that is "the quantity and quality of social, economic and psychological support from family and kinship networks to help individuals and families overcome difficult situations or life events" (AITHS Team, 2010a: 127). It also reflects a broader social and cultural construction of Traveller motherhood as selfless, assuming responsibility for their children's health, and prioritising this over their own health needs.

8.3.2 Intimate relationships: partners or ex-partners (boyfriends, fiancés, husbands)

Traveller women's relationships with men feature prominently in their overall narratives of support, with men providing both emotional and physical support to women. This is with the exception of Megan, whose partner appears peripherally throughout her story. Where he does appear, Megan reasons that both their age and maturity meant that they were both unprepared to have children in the first instance and to also deal with the grief of losing a baby. Although Megan's partner was a non-Traveller man, this did not appear to impact on their overall relationships or other Traveller women's relationships. For example, Catherine continuously referenced her partner, who is not a Traveller man in supporting her both emotionally and physically during both pregnancy losses. Contemporary pregnancy loss scholarship has explored masculinity and pregnancy loss with a focus on the impact of men's role in supporting women during loss (Cook, 1988; Borg and Lasker, 1989; Layne, 2003; McCreight, 2004; 2007; McNiven, 2014). In an Irish context, McCreight (2004) argues that men experience pregnancy loss as a significant life event, which was further compounded by their struggle for recognition of their own transition to fatherhood. It is in this context that men experience self-blame, loss of identity and suppression of grief and anger as they are expected to appear strong for their partners.

Little attention has been paid to intersectional identities and gendered roles of men in this regard. Literature from New Zealand suggests that the impact of pregnancy loss for Maori men is significant and that men did not feel supported by health services or family members[193] (Edwards et al., 2009). Maori men reported that they felt expectations from their family and service providers to be stoic and to support their partner and extended family after loss. Maori men described feeling disconnected from the community and extended family and as a consequence, engaged in isolating coping mechanisms, including "efforts to lose themselves in routine, in work, in physical activity, and, for some participants, in the consumption of drugs and alcohol" (Edwards et al., 2009: 141). In terms of Travellers, with the exception, of Helleiner (2000[1961]) study of Travellers' experiences of infant death, which she describes as the most traumatic events for Traveller women and men, nothing has been written about Traveller men's experiences of pregnancy loss. This research focused specifically on Traveller women, and as a consequence, I did not formally engage with Traveller men on this issue. However, throughout the duration of the research and through professional and personal contacts, I have engaged with Traveller men on the substantive topic. These have been through informal conversations with men in which they have disclosed their own experiences of loss, although not to the same level of detail or disclosure provided by Traveller women in this regard. What is clear from these conversations is that pregnancy loss impacts the entire family unit, including Traveller men. This has been identified in the literature (Helleiner, 2000[1961]; AITHS Team, 2010c: 49) as the death of a family member appears to be a more shared experience by Traveller families and the broader Traveller community given its strong social capital.

In their stories, Traveller women challenge hegemonic narratives of Traveller masculinity by presenting a radically different construction of men than is reported in the popular literature and wider discourse, that is, the perception of Traveller men as aloof and stoic in their relationships with women (Helleiner, 2000[1961]; Hodgins and Fox, 2012). It is also within this lens that Traveller women have been ostensibly portrayed as victims of Traveller men (Helleiner, 2000[1961]; McDonagh, 2000). Traveller masculinity has been constructed in the

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[193] This is referred to as 'Whānau' in the literature (Edwards et al., 2009)

context of racism and the construction of Traveller men as deviant, violent and potentially dangerous, has been reinforced by State policy (Cogan, 1951; Burke, 1956; Lynch, 1956; Government of Ireland, 1963; Pavee Point, 2012). Evidence of this is reflected in historical references to Traveller men by public officials and policy documents as "big, hulking brutes of men" who terrorise and prey on vulnerable housewives (Cogan, 1951; Burke, 1956). For example, in the early 1950s, Independent TD, Patrick Cogan sought stronger legislative approaches to manage Traveller men's behaviour:

> One matter to which I think no reference has been made in the discussion is the growing menace of the travelling tribes in rural Ireland known as tinkers. They are to a great extent beggars and dealers in donkeys, goats and old horses and other similar types of activity […] People living in rural areas, particularly housewives who are left in charge of the house while their husbands are out working, find the tinkers a menace. It is not a very pleasant experience for a housewife living in a remote district, perhaps a mile from her nearest neighbour, to see two or three hulking young men appearing at the door or arriving in the middle of the floor, if the door happens to be open. I know that they only ask for alms, but their very appearance is frightening, and it would be a very brave woman who would refuse to help them. I feel that it is about time the law was tightened up in regard to this matter. [Cogan, 1951: para 2]

This particular depiction of Traveller men became normalised in public discourse, and was proliferated by public officials and mass media. Another TD, Thaddeus Lynch, suggested that Traveller men were "impudent and ill-mannered [...] they go in and threaten the farmer's wife and daughter, if they happen to be alone when the men are working in the fields" (Lynch, 1956: para 2). Lynch was supported by other public representatives fuelling calls for stronger legislation to curb such behaviour (Burke, 1956: para 2). Such racialized gender-based messages and ideological approaches to Traveller men have evolved and become neatly stitched into our social fabric and dominant discourse. For instance, in 2012, Seamus Hughes, a former Fianna Fáil politician and sitting judge who presided over a case involving a Traveller male defendant, stated:

> Nobody has indicated it to me, but I suspect he comes from a certain ethnic background that would give him even more form given the type of behaviour in which some of them engage […] As I've described it before, they are like Neanderthal men living in the long grass, abiding by the laws of the jungle. [Hughes cited by Pavee Point, 2012: 1]

Despite public condemnation and calls for the judge's resignation, the judge did not face any sanctions, did not apologise and remains in post today. In 2012, he made further headlines by calling a Traveller defendant who appeared before him in court as a "pure tinker" (Hughes cited by Cusack, 2012: para 1). Hughes' comments are reflective of a broader collective conceptualisation of racialized masculinity which portrays minority ethnic men as inherently violent and predatory, posing an omnipresent threat particularly to women within the majority population (Hooks, 1992; 2004, 2014; Duru, 2004; Fasching-Varner et al., 2014; Jennings, 2014). This is also in the context of intimate partner relationships which are depicted as oppressively patriarchal.

However, there are two conflicting narratives at play as Traveller masculinity is contested, with Traveller men depicted as both the oppressor and oppressed. Drawing on Hokowhitu (2012) Traveller masculinity is both "imbibed with privilege and denied" as they grapple with their task in performing assimilationist heteropatriarchy while also being resistant to it (23). McDonagh (2000) writes about this in relation to the objectification of Traveller women who have been depicted by researchers and media as being located within oppressive ethnicized paradigms. In reflecting on the heterogeneity of Traveller men (and masculinity) and the assortment of relationships with Traveller women, McDonagh (2014: 8) writes:

> Equally, all men are not the same. They don't particularly want to be like their fathers, or brothers, or uncles. The pressures of patriarchy are pushed on to young feins [Traveller men]. Like sexism towards women, patriarchy brings with it huge peer pressure on men - softness and sensitivity are traits often understood as flaws. Prescribed gender roles require a more diverse expectation of masculinity. Standard male characteristics include power, toughness and physical strength – the big, macho man doesn't just control women, but he also dictates behaviour of other men. If some men are viewed as weak – it's other men who will ridicule them. Outdated and unrealistic expectations are crumbling by lots of women and men who are making all kinds of choices around education, partnerships, marriage, and careers.

For McDonagh, the reification of Traveller masculinity is both reductive and outdated as Traveller men are not homogenous and are constantly redefining their identities as men and as Traveller men. However, according to the McDonagh (2014), Joyce (2018) and others,[194] anti-Traveller racism and discourse has become internalised by Travellers, including Traveller men. Bourdieu's (1989) concept of symbolic violence suggests that individuals or groups internalise negative views of themselves and of their group, such as feelings of powerlessness and worthlessness. For Traveller men, this is reflected in feelings of low self-esteem, poor mental health, high suicide rates and accidental deaths (e.g. alcohol or drug overdose), which, according to the AITHS accounted for almost 50% of all Traveller male external causes of death.

Traveller women in this study expressed concern that men supressed their grief as they focused their attention on their partners. This is something that other researchers have observed (see e.g., Johnson and Puddifoot, 1996, 1998; McGreal et al. 1997, Puddifoot and Johnson, 1997, 1999; Worth, 1997; McCreight, 2004; Murphy, 2009). While acknowledging the lack of

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[194] See for example, O'Connell (1996, 1997) MacLaughlin (1999); AITHS Team (2010a, 2010c)

follow-up and referral to counselling/bereavement services for women in this context, Rosie and others identified the absence of supports for Traveller men. Traveller women were acutely aware of the impact of parental bereavement on Traveller men's mental health, particularly in light of their disproportionate levels of suicide (Pavee Point, 2005b; AITHS Team, 2010a) and lack of spaces for Traveller men to express that grief, both within the and outside the community. These concerns were echoed by all women in the study and while Traveller women's stories are the key focus of this study; women's stories are structured and influenced by their relationships (Smith 1987, 1999), in relationships with themselves, with the broader social, structural and cultural contexts in which they live and with the people around them, including their intimate relationships with men (Mauthner and Doucet, 1998; Brown and Gilligan, 1991; Brown et al., 1991). Therefore, the experiences of Traveller men in this regard merits further consideration.

8.3.3 Relationships with Traveller Community Health Workers (CHWs) and Primary Health Care for Traveller Project (PHCTPs)

Traveller Community Health Workers (CHWs) and Primary Health Care for Traveller Project (PHCTPs) were identified by women as an additional network of support. These relationships are both professional and interpersonal given the fact that the Traveller organisations and PHCTPs are comprised of Traveller workers who may/may not be related to the Traveller women in this study. As discussed in Chapter 1, PHCTPs employ Traveller Community Health Workers (CHWs) who are primarily Traveller women, to provide Primary Health Care to Travellers on a local basis. There are currently twenty-five PHCTPs operating throughout the country, fifteen less than there were prior to austerity (Harvey, 2013; Fay et al., 2017).

For Traveller women in this study, PHCTPs were described as providing additional support outside of their immediate family, Rosie in particular, identifies the PHCTP co-ordinator as a 'big source of support' following the death of her baby. Traveller women acknowledged the importance of having Traveller CHWs to check-in with them even for a 'chat' as noted by Megan. This approach was regarded as useful in terms of signposting women to services, and in relation to normalising Traveller women's experience of loss as Traveller CHWs also shared their own experiences with women. It also provided a safe space for some Traveller women to discuss sensitive issues such as their poor mental health with someone outside the immediate family who has a reference point in terms her life, and without the fear that her children will be taken into care as discussed in Section 8.2.2.

This supports findings from the AITHS which reports that 83% of Travellers receive their health information from Traveller organisations or PHCTPs. The strong relationship in which Traveller CHWs have with Traveller women reflects the value of their work not only for Travellers but for health services. Travellers access to and engagement with mainstream health services prior to the establishment of the PHCTPs were exceptionally poor as reflected in both the *Commission on Itinerancy* and the *Review Body* reports. As noted in Chapter 3, Traveller women's uptake of maternity and other health services was extremely low and was reflected in higher mortality rates for both Traveller infants and women. However, as the AITHS reports, Traveller women's access and engagement with services has greatly improved since these initial reports, with 98% of Traveller women utilising maternity services. It is also demonstrated in the higher uptake of screening services among Traveller women compared to women in the general population. As AITHS (2010a) notes:

- 25% of Traveller women had a breast screening; compared to 13% of women in the general population; and
- 23% of Traveller women had cervical smear test; compared to 12% women in the general population.

Some Traveller women did not have access to PHCTPs in their local area at the time of their pregnancy loss. As discussed in Chapter 1 and Chapter 3, PHCTPs were relatively new in the 1990s, and while the 2000s experienced an expansion of these projects, this was slowly dismantled with the establishment of the HSE and the 'break-even' circular in 2007. This had a devastating impact on PHCTPs, with projects closing across the country due to cuts. Despite the importance of these projects for Traveller women particularly in responding to traumatic events such as pregnancy loss, no further investment has been made to PHCTPs or Traveller health since 2008 (Fay et al. 2017; Fay, 2018; Kavanagh, 2018; Pavee Point, 2018)

8.4 Institutional relationships

Traveller women's stories are intensely focused on their relationships, with institutional, specifically health services and the institutional actors within health services. While policy and literature consistently identifies the need for health services in Ireland to offer appropriate responses to women and their partners following pregnancy loss (McCreight, 2001, 2004, 2007; AIMSI, 2009a; HSE, 2011; 2016a, 2016b; O'Connell et al., 2016; Nuzum et al., 2018), the stories by women in this study indicate otherwise. Traveller women were critical of the treatment they received in health services as they believed they were not always treated with dignity and respect, as discussed in this chapter. This suggests that this approach has failed to materialise amongst frontline service provision over the past 30 years. While agreeing with the literature that quality of care is vital following loss, Traveller women also identify the need for care to be consistent across the pregnancy loss experience; this includes before, during and after loss.

8.4.1 Neglect

In stories of neglect, Traveller women identify either explicit action or *inaction* by institutional actors in their experiences. These stories are primarily told through the lens of failure on the part of health services e.g. the failure of health services to provide adequate medical information during and after loss; failure to act on women's requests for medical care; and failure to offer and/or signpost further services and supports.

8.4.2 Failure to provide adequate medical information

A lack of information provided by health services was identified as a significant issue in Traveller women's overall pregnancy loss narratives. In the absence of medical information, women felt ill-equipped and unprepared for their loss, particularly the physical aspects of loss (e.g. pain, bleeding, etc.). This was particularly frightening for many of the women in this study as they were unaware of what was considered 'common' or 'worrying' with some, such as Deirdre, suggesting that if she had been better informed she could have looked after herself a 'bit better.' However, Megan and Eileen's experiences of non-consent to treatment also highlights another dimension to the provision of information, that in which information was withheld or denied by health services following their caesarean sections (Jewkes et al., 1998; and Jewkes and Penn-Kekana, 2015).

Traveller women recall that where information existed, it was inaccessible and/or irrelevant as in the case of Rosie who describes the information provided by counselling services as 'culturally inappropriate.' Furthermore, while Caroline received information from the hospital, it was of little use, as she cannot read, leaving her feeling embarrassed and isolated. In the absence of information and reassurance by health services, the literature suggests that women tend to internalise blame and guilt (Corbett-Owen and Kruger, 2001). However, it also notes that in the absence of information, women seek out alternative sources such as female relatives; as in the case of Traveller women in this study; traditional face-to-face peer support groups (Layne, 2003; McCreight, 2007, 2008); and more recently, online computer-mediated support groups (McNiven, 2014; Hardy and Kukla, 2015). Contemporary research suggests that online spaces provide women with an alternative location where they can seek peer-led information under the guise of relative anonymity at any time of the day or night (Malik and Coulson, 2008). Traveller women in this study did not identify these mediums as spaces for information, but Megan alludes in her exchange with the oncologist that she could 'look things up,' while Rosie also refers to seeking out information from various sources following the news of her child's diagnosis. However, for other women such as Joanne, Eileen, Alice and Caroline, their experiences predated widespread Internet access amongst Travellers and therefore they describe relying heavily on mothers, sisters and other female relatives for medical advice (see e.g., AITHS Team 2010a).

The literature reviewed also identifies this as a major problem encountered by many women during and after their pregnancy and loss (Cecil, 1994a, 1994b; Layne, 2003; Smith et al., 2006; McNiven, 2014). It suggests that women consistently report the need for clear and accessible information about their loss to enable them to make informed decisions about their care and to understand their experiences. According to Corbett-Owen and Kruger (2001), women reported outcomes in terms of feelings of guilt and self-blame when they were given clear explanations of what was happening to them, and had the opportunity to discuss various options. This is especially apparent when health professionals emphasize that nothing could have been done to prevent their loss. This is something that was absent throughout Traveller women's stories, and instead, women provide examples of where they felt they were being inadvertently blamed by health staff for their loss, as reflected in Rosie's case.

8.4.3 Failure to act on women's requests for medical care

The failure to act on Traveller women's requests for medical attention was also identified as a key issue in Traveller women's overall pregnancy loss narratives. This ground-hog day experience of (re)presenting to the hospital time and time again by Traveller women underscores a frustration with health services. For some women, such as Catherine, delayed treatment was described as further exacerbating grief and pain, both emotional and physical. Many women spoke about the long wait times before seeing health professionals, with Catherine suggesting that this was a systematic way of providing a lesser service by segmenting women based on their ethnicity, marital status and age.

Catherine, as with other Traveller women, also describe feeling like her requests for medical attention were an imposition on staff and were identified as clear barriers to seeking further treatment as they became disillusioned with the level of care offered. Yet, while Traveller women's stories of neglect intensely focus on health services *inaction*, Megan's and Caroline's stories also reflect the ways in which *actions* by health services also resulted in unnecessary pain and trauma. For Megan, this begins during her first pregnancy after doctors inserted a cervix cerclage into her cervix to delay early labour. While stitches are typically removed towards the end of a woman's pregnancy, Megan's stitches were left *in situ* and only discovered three years later during a cervical check. In her interview, Megan describes presenting to doctors with constant physical pain and incontinence during these years, however, she was not referred to secondary care for further investigation. This is something that was highlighted in the All Ireland Traveller Health Study (2010a) and is consistent with existing literature on low referral rates of minority ethnic groups, particularly women, to secondary care (Fox et al., 1991).

8.4.4 Failure to offer and/or signpost further services and supports

Traveller women identified specific gaps in relation to professional supports following loss. One of the key issues that women note is the lack of information, accessible or otherwise, provided by health services during and after loss. Women conceptualised this omission as negligent given that medical professionals have a responsibility to provide appropriate information, guidance and support to patients. In the absence of such supports, Travellers rely heavily on familial supports and in some instances, where they existed,[195] Traveller organisations and PHCTPS. This was true for Rosie who explicitly acknowledged the supportive role of her local PHCTP following her child's diagnosis and death. In particular, she credits the PHCTP co-ordinator in following up and visiting her at home.

8.4.5 Abandonment

In addition to neglect, stories of isolation and abandonment are frequent themes of Traveller women's pregnancy loss narratives, with women recalling feeling spatially and emotionally alone, abandoned and invisible to health services during and after their loss. They also felt that their requests for help were an imposition, with women recalling having to seek out staff when needed. Terms such as 'being left,' 'put away,' and 'hidden' from other women and babies feature prominently in Traveller women's stories of abandonment. These stories are located within obstetric settings with women recalling being admitted to the hospital and placed in a room with very little, if any, interaction with health staff. Traveller women recall that when staff eventually did appear, this was an exception, rather than the norm and it was usually a chaplain or a sympathetic nurse. Women believed that these individuals were acting outside the scope of her duties in a personal rather than in a professional capacity.

These experiences were described as stressful and traumatising for women, particularly where women did not have family members or partners to accompany them to hospital, as in the case of Megan who described her first pregnancy loss as a near-death experience. This was later confirmed by a nurse who told her that she went through 'hell.' Although this incident occurred a number of years ago, Megan continues to reflect on this experience and suggests, as do other Traveller women, perhaps this was simply routine practice at that time. After labour, Megan describes being placed in a room by herself which she believed was 'wrong,' and in trying make sense of her experience, she questions if this was a punishment. Megan, as with all Traveller women in this study expressed the need for professional contact specifically during this period, with support conceptualised as simply 'someone to talk to.'

Traveller women's descriptions of abandonment supports the broader pregnancy loss literature, with research reporting women's feelings of isolation and abandonment after loss. However, this is frequently framed within women's social and interpersonal relationships, rather than institutional settings and actors, as those socio-cultural networks are unable to understand or find appropriate the feelings women were experiencing (Layne, 1996; Kavanaugh and Hershberger, 2005; McNiven, 2014). Where the literature identifies abandonment by health professionals, it does so in relation to women's experiences of emotional abandonment and 'professional avoidance' following loss (Adolfsson et al., 2004; Murphy and Merrell, 2009; Adolfsson and Larsson, 2010). However, Traveller women in this study locate their experiences of abandonment within obstetric settings *during* labour and *after* loss, making their experiences distinct than that reported in the literature. It is from these experiences that similarities can be drawn with the broader literature concerning disrespect, abuse and mistreatment in health services (Bowser D. and Hill, 2010; Freedman and Kruk, 2014; Freedman et al., 2014; Savage and Castro, 2017; Sen et al., 2018) particularly as it relates to Roma women and other minority ethnic women (Centre for Reproductive Rights, 2017).

8.4.6 Non-consent to treatment

Non-consent to medical treatment was an issue that emerged across Traveller women's stories, manifesting in various ways. For Eileen and Megan, this is demonstrated in the performance of medical interventions without consent; with both women reporting undergoing C-sections and only realising afterwards that such procedures took place. Although disconcerting, these practices in Ireland have been documented both by scholars (Kennedy, 2002) and in official State reports, including *The Report of the Maternity and Infant Care Scheme Review Group* (Department of Health, 1997). This report specifically acknowledges institutional mistreatment of women, albeit framed within 'subjective perceptions' of women who had reported "procedures carried out without adequate and informed consent [and] removal of […] dignity and autonomy" (21). This was in the broader context of symphysiotomy[196] pubiotomy (O'Connor[197] and hysterectomy procedures which were carried out by medical professionals in the absence of free and informed consent (Government of Ireland, 1996; O'Connor, 2011; Department of Health, 2014a; Survivors of Symphysiotomy, 2014, 2017; Shaarani et al., 2016; Shaarani et al., 2017)

Women's right to free and informed consent, similar to refusal, is a cornerstone of the right to health as outlined in the 1966 International Covenant on Economic, Social and Cultural Rights. How this is operationalised in a clinical setting varies from health service to health service, but ideally, when a health provider recommends a medical intervention or treatment, there is a legal obligation to inform the patient of both the risks and benefits of the full range of options available. The patient therefore is understood to be entitled to evidence-based, individualised recommendations, and to be supported in the exercise of *genuine* consent. That is, she makes a choice to accept the recommendation or simply decline on the basis of her needs, values and/or what she deems as appropriate. As discussed in Chapter 2, informed consent and refusal within obstetric settings in Ireland is informed by national legislation and policy which suspends women's right to refuse medical treatment and/or interventions if there is a deemed risk to the foetus (HSE, 2017b).

In terms of the institutional approach to consent, the Department of Health suggests that with the exception of mental health, securing patient consent for medical procedures is not a legal

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[196] Symphysiotomy is a medical procedure in which the cartilage that connects the symphysis pubis is severed with a scalpel this followed by unhinging of the pelvic bones (Bergström et al., 1994).

[197] Pubiotomy involves the cutting of the pubic bone to enlarge the pelvis enlargement. Sometimes that was incorrectly mislabeled in medical records as symphysiotomy (O'Connor, 2011).

requirement in Ireland (Department of Health, 2017b: 70). However, this conflicts with its previous position[198] which confirms that consent must be given for medical interventions during childbirth and that women have the right to refuse interventions (Department of Health, 1997). Although this has a caveat as the report states, “the use of technology should take place only with the full informed consent of a woman except in cases of emergency” (29). While the definition of *emergency* is very much subjective and contingent on the attending medical professional, obstetric practice in Ireland operates under impunity when it comes to non-consented treatment as it is sanctioned by the Irish constitution (Government of Ireland, 1983b) and later operationalised and legitimatised through the HSE National Consent Policy (HSE, 2017b). Again, this most noticeably evident in Rosie’s case with medical staff performing a medical examination despite her objections. This was quickly followed by a staff member breaking her waters, again, despite Rosie categorically refusing.

This procedure is used in Ireland to accelerate labour and has been key to the HSE’s ‘active management of labour’ (AML) policy[199] as discussed in Chapter 2. It is a key feature of Ireland’s ‘industrial’ or ‘economic’ approach to maternity care provision (Begley, 2001; Begley et al., 2009). Again, while the HSE notes that verbal consent for such procedures is required, this did not occur in Rosie’s case. Furthermore, even where consent is sought and an informed refusal is provided, this does not have any bearing on a medical professional’s capacity to continue with the intended procedure. As described in Chapter 2, this policy removes women’s autonomy during pregnancy and childbirth, superseding the right to consent for medical procedures. In Ireland, courts and physicians equally give little value to a woman’s right to bodily autonomy as the policy permits the HSE to apply for injunctions from the High Court to compel women to receive treatments should they refuse to comply and not give consent to proposed treatment plans, regardless if such treatment plans are in line with international best practice or not. Cases of HSE high court injunctions against pregnant women have only relatively received media attention namely in the cases of Ciara Hamilton vs. HSE (HSE, 2012) and HSE vs. Baby B (HSE, 2016c). In the latter case, the HSE asked the court for “reasonable and proportionate force [or] restraint” to perform surgery on Ms. B, who was 40 weeks pregnant and did not consent to a C-section. The HSE in this case asked the court’s permission to take proportionate measures to prevent the woman from “absconding from the

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[198] The Report of the Maternity and Infant Care Scheme Review Group (Department of Health, 1997).

[199] This approach was championed by O'Driscoll (1972) and others (O’Driscoll et al., 1969; O'Driscoll, 1993), noting that active management of effectively “controlled” labouring women and decreased the “bottle-neck,” effectively allowing staff to be “deployed productively” (O’Driscoll, 1972: 697).

hospital." In the event that she would have absconded, the HSE sought assurance from the court that the Gardaí would immediately search, arrest without warrant, detain her in their custody for a reasonable period of time and to return her soon as possible to the hospital.

This was also evidenced in the case of Ms. Y, a young woman who travelled to Ireland seeking asylum after persecution and violence in her country of origin. According to her lawyer, prior to arriving in Ireland, Ms. Y was kidnapped, held against her will, beaten and raped repeatedly by the head of a paramilitary organisation (cited in Amnesty International, 2015). Once in Ireland, Ms. Y discovered she was pregnant and sought a termination under Section 9 of the Protection of Life During Pregnancy Act 2013[200] (PLDPA). A number of delays occurred in this case, and similar to the case of Savita Halappanavar (HIQA, 2013, Holland, 2013), Ms. Y's medical records reflect that she was told, "you cannot get an abortion in this country" (Amnesty International, 2015: 41). Ms. Y was suicidal and eventually went on a hunger strike, refusing all food and drink. In early August 2014, the HSE obtained an order from the High Court to force feed and hydrate Ms. Y. While this was abandoned by the HSE, Ms Y. was led to believe that if she accepted hydration and nutrition voluntarily (rather than under a court order that had been issued in respect of her) she would be granted an abortion. Instead, a C-section was performed at 24 weeks and the baby was taken into emergency care by Tusla.[201] In 2016, Ms. Y initiated a civil action lawsuit for damages against the State which includes a claim for alleged trespass, assault and battery; alleged negligence; and alleged reckless and intentional infliction of emotional harm and suffering. It also includes a claim for alleged breach of duty, alleged false imprisonment and alleged unlawful deprivation of liberty. Ms. Y further claims alleged unjustified intentional negligent infringement of wrongful interference with and/or failure to vindicate her rights under the Constitution and her rights under the European Convention of Human Rights[202] (Amnesty International, 2015). These incidents, while appearing extreme, are not simply unique to Ireland, with similar practices occurring in other jurisdictions, particularly for indigenous and minority ethnic women (CEDAW, 2006; Janevic et al., 2011; Colombini et al., 2012; Diaz-Tello, 2016; Khosla et al., 2016; Janevic et al., 2017; Watson and Downe, 2017).

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[200] See Quilty et al. (2015) for further discussion.

[201] TUSLA is the Child and Family Agency

[202] See Amnesty International (2015); Quilty et al. (2015); and Enright and Londras (2014) for further discussion.

8.4.7 Discrimination

Throughout their stories Traveller women describe feeling paradoxically *hyper visible* or completely *invisible* within health services and other institutions. Traveller women were acutely aware of their ethnicity within health and other institutional settings. While women do not recall being asked about their ethnicity at any point during their pregnancy, they contend that health services intuitively made assumptions that they were Travellers based on their appearance, address, surname, etc. Maternity services in Ireland are one of the few institutions that require demographic information, including ethnicity to inform clinical practice and ensure compliance with the Newborn Bloodspot Screening programme. It is also relevant for the accurate reporting of Travellers given the HSE's policy to screen all Traveller babies for Classical Galactosaemia[203] (Coss et al., 2013; Hamid et al., 2014). This was something that has been suggested in all major Traveller policy documents since 1963 when *Report of the Commission on Itinerancy* recommended the collection of such data to monitor Travellers uptake of health services and their outcomes (Government of Ireland, 1963: 51). Pavee Point, alongside with other Traveller organisations have been key in promoting the inclusion of a universal ethnic question in all statutory data sets in line with data protection law and human rights principles[204] since the 1990s (Kavanagh, 2016). While some agencies have adopted an ethnic question, others, have been reluctant to do so, citing that it could be perceived as discriminatory and disrupt the rapport between service provider/user. However, as Traveller women indicate in this study, their racialized identity remained hyper visible amongst staff, even in the absence of any formal data collection and their experiences of discrimination and racism still occurred.

In their stories, Traveller women link negative experiences with institutional actors with their racialized hypervisibility. This is demonstrated in women's recollections of racial and micro-aggressions displayed by institutional actors (Pierce, 1995; Sue et al., 2007; Janevic et al., 2011; Colombini et al., 2012; Mowatt et al., 2013; Slaughter-Acey et al., 2013; Slaughter-Acey et al., 2016; Janevic et al., 2017; Watson and Downe, 2017). This includes delayed care,

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[203] Classical Galactosaemia is an autosomal recessive condition which occurs in about 1 in 450 Traveller births, compared with 1 in every 36,000 births for non-Travellers births (Coss et al., 2013; Hamid et al., 2014). Positive results of these tests, including those of which are Traveller infants are reported by the HSE in the National Newborn Bloodspot Screening Programme Report (HSE, 2013)

[204] A human rights approach to ethnic data collection means that (Kavanagh, 2016: 3):

- There must be a universal question (applied to everyone not just minority ethnic groups) which is answered based on voluntarily self-identification; and
- Collected data is aggregated and anonymised to avoid identification of specific individuals;
- Data must only be used for the purpose for which it was collected;
- Data must be available in a timely manner and must be analysed in consultation with organisations representing minority ethnic groups.

neglect, abandonment and perceived threats, as in Megan's case. While some women such as Rosie suggests that these interactions were examples of unconscious ignorance, prejudice, and racist stereotyping, Catherine, Megan and a number of others considered the inflections as an intentional way to exclude Traveller women, leaving them feeling embarrassed, rejected, disrespected and unfairly treated. In some instances, women felt that as Travellers, their racialized hyper visibility led to a lower standard of care and a poorer quality of service. For Megan and Catherine, this was described as similar to being treated like animals. This parallels findings in international scholarship which documents indigenous and minority ethnic women's experiences of unfair medical treatment in obstetric settings (Kennedy and Murphy-Lawless, 2002; ERRC, 2004, 2006, 2010; Kavanaugh and Hershberger, 2005; Janevic et al., 2011; Chadwick et al., 2014; Pohjolainen, 2014; Zacher Dixon, 2015; Fernández, 2015; Curran, 2016; Albert and Szilvasi, 2017; Chadwick, 2017b, 2018; Center for Reproductive Rights, 2017; Janevic et al., 2017; Chattopadhyay et al., 2018).

Given the focus of this study is on Traveller women's experiences of pregnancy loss, service providers were not consulted to any large degree on how, if any, their perceptions of Travellers influenced their practice. However, it is well established in the literature review that power, difference and identity have a considerable impact on shaping interactions in clinical settings, with research indicating that minority ethnic groups receive lower quality health services and are less likely to receive medical procedures than those from the majority population (Thomas, 2001; Ferguson and Candib, 2002; Snowden, 2003; Chung et al., 2006; Laditka et al., 2006). This also supports findings from the AITHS (2010c) in which 66.7% of health service providers openly admitted that anti-Traveller racism existed within health services and that discriminatory practices resulted in substandard treatment of Traveller service users.

While the AITHS provides a broad focus on health services in general, findings from the literature review also identifies similar findings, with discrimination and racism, based on ethnicity, socio-economic status, education, professional status and single motherhood, as mitigating factors which exacerbates women's negative experiences in obstetric settings. For example, Mannava et al. (2015) identify verbal abuse, ignoring or ridiculing patients, neglect, physical abuse towards women, poor communication, unwillingness to accommodate traditional practices, and authoritarian or frightening attitudes, amongst others as a result of provider beliefs and prejudices. Roma women in particular have been identified as experiencing such hostility, discrimination and abuse in obstetric settings throughout Europe.

This includes experiences of segregation, racial harassment and humiliation, neglect, physical restraint and abuse during childbirth, and failures related to informed consent and decision-making with regard to medical treatment (Zoon, 2001; Curran, 2016; Center for Reproductive Rights, 2017: 7). Qualitative accounts by Roma women echoes Traveller women in this study, particularly in relation to feelings of humiliation and degradation, with frequent references to being treated like animals (see e.g., Center for Reproductive Rights, 2017; Watson and Downe, 2017). These interactions are classified according to interpersonal exchanges between Roma women and service providers, but they are products of structural and systemic racial oppression which are reinforced at policy levels within Member States.

However, some women were ambivalent in framing their experiences as discrimination and/or racism. Megan, for instance, demonstrates ambivalence throughout her story in calling out racism and/or discrimination. In some interactions, she does so confidently as in the interactions between staff following the death of her baby, particularly the hospital chaplain. However, in the case of her local parish priest who came late to her child's funeral without apology, she begins to postulate how she *felt* that it could have been a result of racism, yet does not commit, quickly reversing her position before commenting that people should not be treated in that way regardless of who they are. As the literature indicates, discrimination and racism extends beyond interpersonal exchanges and/or explicit micro-aggressions by individuals, either on an intentional basis or indirectly (Anthias and Yuval-Davis, 1989; Jones, 2000; Fassin, 2011a). As such, long-standing racialized practices seep into social and economic structures, systems and processes. This appears as subtle, hidden and normalised, thus reinforcing the power and privilege of the majority population (Bonilla-Silva, 2013). It is within this context that the needs and rights of the majority group become prioritised over those of the minority groups. In their narratives, Traveller women frequently juxtapose their hyper visibility with being invisible to health services, particularly in recognition of their particular needs as Traveller women. This includes the importance of the extended family visiting the hospital following a bereavement, as in the case of Rosie. It is also reflected in the lack of accessibility of services and institutions, specifically, in relation to the provision of information, or lack thereof, as discussed in the section below.

Perinatal health policy and by extension, health services are required to treat women equally based on woman-centred care, contingent on each woman's individual circumstances. However, the HSE frequently conflates this with treating women equally and being 'oblivious difference' to difference (HSE, 2016a: 4-5). This is apparent in Ireland's *National Maternity Strategy* (Department of Health, 2016), which ignores Traveller women entirely, despite them having the worst perinatal outcomes amongst any other group in Ireland. Given Traveller women's higher parity rates and frequency in accessing these services, their inclusion in this regard is imperative. The omission of Traveller women, and Travellers more generally, in policy has resulted in their exclusion in mainstream services as they are rendered invisible and their particular needs are overlooked.

Similar to what Mowatt et al. (2013) argue in relation to back bodies in white-dominated societies, invisibility is a central aspect of being a Traveller woman in an Irish 'settled'-dominated society. Traveller women's bodies have historically constituted a site where the vast and largely problematic complexities of gender and ethnicity are revealed and contested, particularly in relation to 'social modernisation' and national settlement policies, as noted above and discussed in detail in Chapter 3. Additionally, Traveller women's bodies come into view when conceptions of sexual subjection, social disparities or socio-political agendas require it (McDonagh, 2000). As McDonagh (2000) argues, Traveller women's bodies become hyper visible in popular mass media as spectacles to be ridiculed (i.e. *Big Fat Gypsy Wedding/Traveller 'expose'* programmes) or when it suits socio-political agendas to use Traveller women, particularly Traveller mothers, as scapegoats, blaming them for the systemic inequalities, particularly in relation to children (e.g. children's poor health, children's non-attendance and progression in school, etc.) This ideology is present in State discourse and policy, featuring prominently in the *Report of the Commission on Itinerancy*; with Traveller mothers effectively blamed for Travellers' high infant mortality rates as they left the hospital "too early after birth," returning to inhabitable "dirt, squalor" and untidy sites (Government of Ireland, 1963: 50-51).

This hyper visible/invisible dichotomy also mirrors the State's approach to Travellers, with hypervisibility associated with problematisation of Travellers requiring particular responses from the State. The State has also demonstrated its ambivalence in relation to the recognition of Travellers as distinct from the majority population. This is most notable in the State's refusal to acknowledge Traveller ethnicity until recently and under duress by national and international human rights organisations and monitoring bodies (see Chapter 3). This confusing approach has been adopted by various governments departments and agencies under their remit, including the Department of Health and HSE.

8.5 What we can learn from positive experiences

Overall, Traveller women felt a lack of support, care, respect and awareness of their particular needs (e.g. literacy by health services). As highlighted in Chapter 9, these experiences are told through narratives of neglect, abandonment, non-consent to treatment and discrimination. These experiences left Traveller women feeling distressed, isolated and traumatised. However, women also identified positive experiences with health services as outlined in Chapter 9. In both Rosie and Deirdre's cases, they were provided with personalised emotional and physical support and believed that they were supported or as Rosie notes, treated 'as a human being.' In both instances, Rosie and Deirdre felt they were treated with respect and dignity; their loss was recognised and acknowledged (Corbett-Owen and Kruger, 2001), and as a consequence, their experiences were regarded as positive. Women recognised that the outcome, that of loss, would be the same but their *experience* could have potentially been different. This supports findings of pregnancy loss research to date which suggests that what matters most to women is that they feel respected, supported and reassured by competent staff (see Chapter 2). This underscores the importance of attending to qualitative aspects of maternity service provision, with Traveller women suggesting that it is a valid indicator of the *quality* of maternity care provided. It also matters in terms of outcomes for Traveller women, including longer term well-being. Additionally, it matters for their surviving babies, their partners and family members, and for the wider community.

However, as Murphy-Lawless (2015) and Kennedy (2002, 2004) point out, quality of care may not be necessarily prioritised by Irish maternity services as it focuses intensely on birth *outcomes* as a vital indicator of its success i.e. the survival of the infant and the woman, rather than women's qualitative pregnancy and birthing experiences. This is in keeping with the State's commitment to reducing infant and maternal mortality rates as per national and international health policies and strategies. This approach to maternity care is frequently framed within the institutional discourses of safe motherhood and obstetric safety (Davies et al., 2000) and it is used to legitimise the claim that Ireland is 'one of the safest places in the world to have a baby' (Carroll, 2010; RCPI, 2017). Aside from data gaps in terms of recording and calculating maternal deaths (Murphy-Lawless, 2015) this discourse in many ways creates unrealistic expectations of Irish health services, as adverse events, such as loss, will inevitably occur, regardless of the clinical environment. It also obscures the broader social, political and economic context in which services are located. This includes a lack of resources and prioritisation to implement policy, coupled with massive disinvestment in maternity service provision. Furthermore, the ‘safety’ of health services does not mean that women will not experience negative treatment (Chadwick, 2018; Chattopadhyay et al., 2018). Rather, in the absence of considering women’s experiences of childbirth and labour, health services will continue to be driven by those very outcomes. Therein lies the paradox of ‘safe’ birth, those which reduce maternal and infant deaths while at the same time causing distress and trauma to women, as reflected in the stories in this study.

8.6 How Traveller women experience pregnancy loss in Ireland: structural level

Women’s experiences of pregnancy loss in Ireland have been mediated by paternalistic and patriarchal policies which inform our maternity services (Murphy-Lawless, 1993, 1998, 2015; Kennedy, 2002, 2004, 2012). As Murphy-Lawless (2015:207) observes:

> The consultant-driven model of birth provision focused on an interventionist birth culture impedes the voices and actions of women and midwives alike. It is notably sustained by a continuing deference to professional, male-focused authority, in line with the power of the ‘patriarchal dividend’. It cannot be stated strongly enough that it is not safe, cost-effective, or evidence-based and that it cannot stand up against international data.

Described as something of a “bellwether for health services in the Ireland,” (Irish Times View, 2017: para 1) maternity services have been subject to numerous national scandals, including symphysiotomy, a miscarriage scandal, investigations into maternal and infant deaths, and most recently, major failures in cervical cancer screening[205] (see Chapter 2). Subsequent inquiries have identified the systemic nature of institutional failures in ensuring safe and quality services for women and their infants (Kennedy, 2002, 2004, 2012; HIQA, 2015; Murphy-Lawless, 2015). These reports have called for national implementation of consistent delivery models to ensure that all pregnant women have access to the ‘right level of safe care and support on a 24-hour basis’ (HSE, 2013a:132—3). While these events have acted as catalysts in attempts to re-position and shape the maternity policy landscape in Ireland, a significant shift in practice on an institutional level remains outstanding, as evidenced in the literature review presented in Chapter 2 and by the findings of this study.

Women’s experiences in this regard are located in an already overstrained and impoverished hospital infrastructure which contends with the highest birth rate in the European Union (Murphy-Lawless, 2011, 2015; Eurostat, 2017). This has been compounded by economic crises, particularly in 2008 which resulted in massive reductions in its overall budget, leading

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[205] Cervical screening falls under the remit of obstetrics and gynaecology services in Ireland provided by maternity services.

to staff shortages and taking Ireland below internationally recommended ratios to maintain clinical safety (KPMG, 2009; HSE Chief Medical Officer, 2014; O'Regan, 2014; Murphy Lawless, 2015: 208). As discussed in Chapter 7, litigation and pay-out on behalf of maternity services has increased by 80% between 2010 and 2014, with the HSE paying out approximately €58 million to women and their families in 2014. Yet, aside from external scrutiny which is often focused on health staff rather than a health system, internal struggles are evident within maternity services. This is particularly true for midwives as they grapple with increased working hours, salary cuts and increased direct taxation and regressive indirect taxation measures as a result of the State's EU/IMF 'bailout' package. Such work conditions have placed a burden on recruitment and retention of midwifery and nursing staff (Gouda et al., 2015), with almost three out of four of final year nursing/midwifery students indicating that they are considering leaving Ireland to seek employment elsewhere (INMO, 2018a). According to Donohue (cited in INMO, 2018b: 7):

> The offer of a permanent contract for an extremely low paid job with poor working conditions is simply not attractive for nursing and midwifery interns. The shortage of skilled and experienced nurses and midwives to support the education of students will also mean there will be further deficits going forward.

A further dimension to this, which is often overlooked within public discourse, is the complex relationship and interactions between midwives and maternity services. This includes a lack of autonomous professional practice in favour of male-centred consultant obstetric care; the antithesis of what midwives have been trained to do. It is also mediated by larger structures of oppression and domination which are based on sexism, racism, classism, ableism and heterosexism (Hankivsky and Cormier, 2009).

Traveller women are located within this structural reality but their experiences of pregnancy loss are different as the structural context in which they live starkly differs from that of women in the majority population. Traveller women's individual and collective narratives in this regard are shaped by mutually constituting factors of social location and structural disadvantage which is predicated on the intersection of ethnicity and gender and the negative outcomes of the two, racism and sexism (Collins, 1990; Crenshaw, 1991, 1997; Essed, 1991, 2001). These systems of oppression are mutually constituted and work together to produce Traveller women's unequal, excluded, marginalised position within Irish society. For specific groups of Traveller women (e.g. Traveller women with disability, LGBTQI Traveller women or Traveller women in prison), the layers of inequality and exclusion are multiplied (Crenshaw, 1991, 1997; Doyle, 2017). This is demonstrated at micro, meso and macro levels and articulated both overtly and covertly (Collins, 2017a).

8.6.1 Overt discrimination: micro/everyday encounters

On a micro level, this study argues that Traveller women's pregnancy loss experiences are rooted in everyday experiences of 'gendered racism' (Essed, 1991, 2001), that is, "racisms and genderisms [that] are rooted in specific histories designating separate as well as mutually interwoven formations of race, ethnicity and gender" (Essed, 2001: 1). This is demonstrated in everyday micro-aggressions as identified by Traveller women in this study. For example, in Rosie's case she describes two separate incidents in which health staff suggested 'Traveller exogamy' as a determining factor in her child's death. This, despite, the fact that Rosie and her husband were not related. In Megan's case this is reflected in her interactions with a hospital chaplain who questions her capacity to care for her surviving son, specifically referring to the fact that she was a single woman and a Traveller, living with her immediate family. On further consideration, Megan understood her situation to be an ideal situation given her close relationship with her mother and the level of familial support she received following the death of her baby.

Beyond this study, however, Traveller women's experiences of discrimination and racism have been documented primarily by Traveller organisations. For example, in one of the very first surveys on Traveller women and discrimination, 71% of Traveller women surveyed reported that they experienced verbal abuse because they were Travellers, with 25% of these including physical violence (Pavee Point, 1997). This body of evidence of discrimination and racism directed towards Travellers has been further developed and documented over the years particularly by Traveller organisations, civil society organisations[206] and academics. As discussed in Chapter 1 and Chapter 3, research consistently indicates high levels of discrimination experienced by Travellers. For example, out of the 658 complaints made under the Equal Status Acts in 2016, 416, or 62% of indicated membership of the Traveller community as a grounds (Workplace Relations Commission, 2016). This suggests high levels of discrimination experienced by Travellers in Ireland. This is complimented by McGinnity et al. (2017) who found that Irish Travellers are 38 times more likely than the majority population to report discrimination in shops, pubs and restaurants. According to Collins (2017b), "the facts

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[206] For example the European Network Against Racism Ireland's Racist Incident Reporting System (iReport) has been one useful tool to capture data on Travellers' experiences of racism.

that can no longer be ignored. Now it's not just Traveller organisations who are highlighting this situation but it is also independent organisations talking about hard evidence" (para 2):

It is not clear from the WRC report or the analysis from McGinnity et al. (2017) the extent to which discrimination is gendered and vice versa. An intersectional lens is rarely applied in relation to equality data, which makes it difficult to extrapolate a comprehensive analysis of Traveller women's experiences in this regard. Notwithstanding the important reports, the absence of official disaggregated data on the basis of ethnicity and gender makes it more challenging to locate the intersectional dimensions of discrimination and racism for Traveller women. Despite being government policy,[207] official State data on the situation of Travellers is seriously lacking as ethnicity is not included as an administrative category in official State surveys[208] and official data collection systems, including health. This effectively obscures the experiences of Travellers' marginalisation in Ireland, particularly in terms of equality data sets such as the Survey on Income and Living Conditions[209] (SILC) and the Quarterly National Household Survey[210] (QNHS), both of which are reported at European level to monitoring employment, poverty and social inclusion amongst Member States. Ireland's data deficit has been highlighted by a number of UN treaty-monitoring bodies, European institutions and equality and human rights bodies within Ireland (Kavanagh, 2016a).

8.6.2 Covert discrimination: meso/macro level

As discussed in the literature, racism and discrimination are not always direct, explicit or overt acts which can be tangibly observed and/or quantified as they operate beyond the individual level. As McDonagh (2013) observes, "the parameters of the racism experienced by Travellers has changed over the past 10 years. A more covert racism, a harsher racism and a more difficult

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[207] A number of policy framework documents commit to the collection of 'equality data,' inclusive of ethnicity (e.g.) *National Traveller and Roma Inclusion Strategy (2017-2021); Second National Strategy on Domestic, Sexual and Gender-based Violence (2016 – 2021), National Strategy for Women and Girls (2017-2020); and Migrant Integration Strategy.*

[208] With the exception of a universal ethnicity/cultural background question into the national census in 2006. See Kavanagh (2016) for further information.

[209] SILC data plays a critical role in meeting Irish national requirements in the areas of poverty, social exclusion and household income. SILC is the only data source in Ireland, which combines health status, income and other socio-economic predictors such as class, education and family origin. This is a key source of equality data for Ireland as it reports on a number of key national poverty indicators, including the 'at risk of poverty' rate, the consistent poverty rate and rates of enforced deprivation. This data is included in Eurostat's European Survey on Income and Living Conditions (EU-SILC), which is comparable cross-sectional and longitudinal multidimensional data on income, poverty, social exclusion and living conditions in EU Member States (Kavanagh, 2016).

[210] The Quarterly National Household Survey (QNHS) is the Irish implementation of the European Labour Force Survey (EU LFS) which provides information on key labour market indicators. Statistics reported in the QNHS are included in Eurostat's European Union Labour Force Survey (EU LFS) and the data is considered a key source for European statistics about the situation and trends in the European labour market. While the purpose of the QNHS is the production of quarterly labour force estimates, there is also a provision for the collection of data on 'special' survey modules; this included an equality module in 2004 and 2010. Although the sample included Travellers, it was too small to allow for separate analysis (Russell et al., 2008). Travellers organisations alongside UN and Human Rights bodies have recommended that alternative sampling methods should be considered in order to ensure a representative sample of Travellers, Roma and other minority ethnic groups, which may be considered 'hard-to-reach' (Kavanagh, 2016).

racism to challenge has emerged" (13). This nuanced racism in which McDonagh refers to can be understood from the lens of structural racism, that is:

> The totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice. These patterns and practices in turn reinforce discriminatory beliefs, values, and distribution of resources. [Bailey, 2017: 1453]

Structural racism is a dimension of structural violence, which is, "violence exerted systematically—that is, in-directly—by everyone who belongs to a certain social order" (Farmer, 2004: 307; Powell, 2007). Structural violence is reflected in Travellers' poor quality of access, participation and outcomes within respective policy areas, including health, accommodation, education, employment and criminal justice. For example, in terms of accommodation, Travellers represent 9% of the homeless population whilst only accounting for less than 1% of the national population (Grotti et al., 2018). Where Travellers are living, conditions are often precarious, with 15% of all Travellers living in 'temporary accommodation' while overcrowding is seven times the national rate (Department of Housing, Planning and Local Government, 2017; Grotti et al., 2018). This is something that has consistently increased annually, for example, in the period 2008–2017, there has been has been a 223% increase of Travellers 'sharing accommodation' (see Table 2). According to Fay et al. (2016) "sharing is a euphemism for Travellers living in conditions in chronic overcrowding […] on sites that are often flooded, rat infested and lacking in everything but basic facilities such as shared tap" (3).

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
Travellers sharing accommodation	437	345	390	451	492	604	663	727	862	963	1,115

Table 2: Number of Travellers in 'shared accommodation' over a 10-year period (Department of Housing, Planning and Local Government, 2009, 2012, 2015, 2017)

These issues cannot be decoupled from the overall national accommodation crisis that Ireland is experiencing, which is due to a lack of supply, increasing demand and increasing rents. However, for Travellers, this a consistent issue due to a lack of implementation of Traveller Accommodation Programmes[211] by local authorities. The 2018 figures released from the

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[211] The Housing (Traveller Accommodation) Act 1998 requires each local authority, following a consultation process, to prepare, adopt and implement 5-year Traveller Accommodation Programmes (TAPs) to ensure the provision of accommodation for Travellers. Specific targets are set under the programmes, with funding provided by the State (Government of Ireland, 1998).

Department of Housing Planning and Local Government reports that local authorities have consistently failed to meet Traveller-specific targets every year since they were made mandatory 18 years ago. This includes a gross underspend in allocated budgets, with €55 million provided for Traveller accommodation remaining unspent by local authorities since 2000. A review by the Department notes that objections from local residents from the majority population, and consequent political pressure exerted by elected representatives, delay the planning process, sometimes for years, which has an impact on local authority's capacity to deliver targets.[212] In 2018, only ten out of thirty-one local authorities have drawn down their Traveller accommodation budget. With the exception of Roscommon, where the budgets have been drawn down, there has been a substantial underspend (See Appendix XII). The lack of delivery of Traveller accommodation has effectively forced Traveller families to become homeless by proxy, in the absence of delivery of Traveller accommodation by local authorities and a lack of supply in the private rented sector. Yet, even where private accommodation exists, the overwhelming majority of landlords[213] would not rent to Travellers which is reflected in the Ginnity et al. (2017) Discrimination Report (see Chapter 1, Section 1.1)

This situation places families in precarious living situations, as demonstrated in 2015 in Carrickmines, where ten Travellers died following a fire on a site. Similar to other Traveller sites, the Carrickmines site was intended to be temporary, yet it was still occupied after eight years due to the failure of local authorities to provide Travellers with permanent accommodation. According to Fay (2015):

> Many Traveller families throughout Ireland are being forced to live in overcrowded and dangerous situations due to the impact of the housing crisis. The difficulties in accessing the private rented sector are exacerbated for many Travellers who continue to experience widespread discrimination and find it nigh on impossible to rent from private landlords. This is in addition to the cuts made by the Government to Traveller accommodation under the guise of austerity measures with the budget reduced from €40m in 2008 to €4m in 2013. [Fay, 2015: para 4]

One of the most striking features of this incident was the initial reaction to the families which included a stream of public sympathy and support. This was short-lived, as when local authority attempted to accommodate the remaining family members on local authority land it was met with objections from local residents, including some residents who blocked the families' access

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[213] According to DKM Economic Consultants et al. (2014: 47) 82% of landlords said they would not rent to Travellers; while 95% of landlords were happy to rent to 'non-Irish nationals' and 66% said they would rent to social housing tenants. The reasons given for not renting to Travellers was 'worry about damage to property'; 20% of landlords said they based their view on previous experience. This was supported by estate agents, with only 24% believing that their clients are willing to rent to Travellers (59).

to the land with their cars. The residents argued that they had not been consulted by the local authority. The local authority responded to the residents by moving the bereaved family to a public car park without access to basic facilities such as water or sewerage. The site was described as 'not ideal' by the local authority (O'Doherty et al., 2015). Despite condemnation from Traveller organisations, allied groups, politicians and individuals, the local residents received a wide range of support from the public. For example, *Irish Times* held a poll in which 72% of readers[214] stated that they supported the residents' protest (Holland, 2015). This also played out in national media, and in particular, in the comment sections of the Journal.ie, one of the most popular online news sources in Ireland. While these comments reflected the breadth of explicit racism against Travellers collectively, they also illuminated aspects of gendered racism. Some examples include (Kavanagh, 2015b):

> They want equal rights but yet they treat traveller woman as virtual slaves who are denied any chance of a career outside of being barefoot and pregnant
>
> Travellers want everything handed to them. They don't work but yet have bucket loads of children and expect the state to pay for their upbringing
>
> Travellers have human rights the same as every other citizen in the State, they're not a separate ethnic minority as some bleeding hearts like to claim. It's not unreasonable either to ask where the source of their wealth comes from, do they pay taxes on their income, why there appears to be inherent violence within the community, why is their sexulisation [sic] of girls and why are women condemned to lives of endless child rearing with the community.

Similar to the gendered and racialized construction of Traveller men as discussed in Section 8.3.2, these comments, are reflective of earlier gendered and racialized constructions of Traveller women by the State as observed in the *Report of the Commission on Itinerancy* (Government of Ireland, 1963). Moreover, while these comments demonstrate explicit contempt for Travellers in Ireland, they are not simply reflective of individuals but also of public officials, including politicians, judges and more recently, a presidential candidate articulating similar iterations (Barrett, D. and O'Dowd, 2017; Joyce et al. 2017; Joyce, 2018; McGee, 2018). This is in the broader context of a lack of pro-active measures on racism in Ireland, including a clear policy framework. This is reflected in the government's disbandment of the National Consultative Committee on Racism and Interculturalism (NCCRI) in 2008 and in the absence of a new and/renewed National Action Plan on Racism. This, despite a significant increase in the reporting of racist hate crimes[215] in Ireland and numerous

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[214] This is based on 4,800 respondents

[215] Drawing on Taylor et al. (2017: 2) this study acknowledges the broad range of identity groups, who also experience hate crime in Ireland including, Travellers and Roma; racialized minorities; disabled people; lesbian, gay and bisexual people; and communities affected by sectarianism.

recommendations from UN treaty-monitoring monitoring bodies, European institutions and equality and human rights bodies (Carr, 2017; Joyce et al., 2017; O'Curry, 2017; ENAR, 2018).

Moreover, subsequent to these events, a national fire safety audit of Traveller accommodation was conducted. The objective was to ensure that practical and appropriate fire safety measures, which contribute to preventing loss of life and serious injury in local authority Traveller accommodation, would been applied systematically across the country. Traveller organisations worked with the National Fire Safety Office and local authorities to support the audits. Yet, despite Traveller organisations receiving an assurance that the audits would not result in forced evictions, a number of evictions took place throughout the country, leaving families homeless or forcing people to stay at homes and bays of extended family members. This broader structural landscape of discrimination, racism, sexism, marginalisation and inequality is integral to understanding Traveller women's lived experiences, including that of pregnancy loss.

8.7 Using intersectionality theory to understand Traveller women's structural experiences

The level of both political and public animosity towards Travellers is linked to broader structural inequalities which are manifested in Travellers' homelessness, substandard living conditions, high levels of poverty, over-representation in prisons, and poor outcomes in terms of employment, education and health. The literature reviewed argues that racism is a key determinant of population health and an indicator of health inequalities (Krieger, 1993, 200a, 2000b, 2014; Krieger et al., 1993; Williams and Collins, 1995). This is often presented through the lens of interpersonal racism and the consequences of perceived unfair treatment on an individual's health, particularly their psychological health (see e.g.,Gee and Ford, 2011; Reskin, 2012; Krieger, 2014; Bailey et al., 2017). This study acknowledges that structural violence has a substantial role in shaping the distribution of social determinants of health of Travellers, including Travellers' persistent health inequalities. This produces a particular experience of health services as reflected in Travellers' lower levels of trust matched with the acknowledgement from health services providers that racism and discrimination exists within the sector resulting in substandard treatment of Traveller service users (AITHS Team, 2010c). However, this study also suggests that structural violence does not adequately address the gendered dimensions of Traveller women's health inequalities, nor does it account for the particular individual experiences of Traveller women outlined in this study. Therefore, this study proposes a synergistic approach by using intersectionality theory to bring together both the gendered and racial dimensions of structural violence to provide a holistic understanding of Traveller women's experiences in this regard. It does so by looking at Traveller women's pregnancy loss experiences through the lens of obstetric violence, reflecting the particular obstetrical dimension of structural violence.

8.8 Obstetric violence

Obstetric violence is global issue (d'Oliveira et al., 2002; Small et al., 2002; Kruger and Schoombee, 2010; White Ribbon Alliance, 2011; Silal et al., 2012; Chadwick et al., 2014; WHO, 2014; Sadler et al., 2016; Shabot, 2016; Chadwick, 2018; Schwartz, 2018; Solnes Miltenburg et al., 2018) and there is clear evidence from the literature, which suggests that obstetric violence has been a feature of many women's maternity experiences globally, including Ireland (d'Ambruoso et al., 2005; Ciara Hamilton v. HSE, 2012; d'Oliveira et al., 2012; Fernández, 2013; HIQA, 2013; UNHRC, 2014; HIQA, 2015; da Silva et al., 2016; Delay, 2016; Delay and Sundstrom, 2017; Boylan, 2018). This is demonstrated in the evidence provided in a number of investigations into Irish maternity services (AIMSI, 2009a; HIQA, 2013; HIQA, 2015; Boylan, 2018) and the historically widespread practice of symphysiotomy and pubiotomy procedures on women in maternity hospitals in the absence of free and informed consent (Department of Health, 2014a: 68; O'Connor, 2011; Jillson et al., 2012). It is also reflected in the historical legacy of abuse and mistreatment of girls and women in institutions such as Magdalen laundries and Mother-and-Baby homes as discussed in Chapter 2. Contemporary examples are demonstrated in the routine practice of artificially rupturing women membranes (ARM) to induce labour (also known as "breaking the waters") without consultation or consent, as in the Hamilton case; to the performance of coerced and/or forced caesarean sections on women, despite explicit refusal, as with HSE v B (HSE, 2016c).

However, most of this literature represents women's experiences as largely homogenous and frequently predicated on their gender, marital status and socio-economic status. With the exception of a handful of scholars such as Murphy-Lawless (1993, 2015), Tobin and Murphy-Lawless (2014), and Kennedy (2002, 2004, 2012) is little reference to minority ethnic women's experiences of obstetric violence in Ireland. This despite documented evidence indicating racism, discrimination and poorer quality of treatment reported by migrant and minority ethnic women in obstetric settings (Kennedy and Murphy-Lawless, 2002; AITHS Team, 2010a; Pohjolainen, 2014). It is also in the broader context of disproportionately poorer perinatal outcomes for minority women, including higher rates of infant/maternity mortality and morbidity (AITHS Team 2010b; O'Hare et al., 2015).

This experience is not unique to Ireland, as indicated in the literature review. Globally, indigenous and minority ethnic women have a shared collective experience of institutional mistreatment and abuse, particularly in relation to their reproductive and perinatal health. Indigenous and minority ethnic women's bodies have often been the terrain in which the majority population has assumed domination and control through abusive and violent obstetric practices (Roberts, 1999; Castro et al., 2015). This domination becomes inscribed both on, and in, women's bodies, leaving physical traces left by centuries of domination, segregation and stigma (Farmer, 2004; Fassin, 2011b: 429). Examples of this are reflected in the experience of 'medical apartheid' upon enslaved African American women in the United States (Washington, 2006; Chinyere-Oparah et al., 2015), and the global[216] and systemic nature of forced or coerced sterilisation policies targeting minority women, particularly Roma women (Curran, 2016; Center for Reproductive Rights, 2017).

Traveller narratives of pregnancy loss demonstrate the ways in which obstetric violence is operationalised at both individual, interpersonal and structural levels. While this study recognises that similar experiences of obstetric violence can be shared by other women in Ireland, Traveller women's experiences are pronounced by racialized aspects of treatment by health services, suggesting that mistreatment is defined in this context by gendered racism. Traveller women's pregnancy loss narratives highlight some of the micro-level dimensions of obstetric violence as defined in the literature. This includes neglect, abandonment, non-consented treatment and discrimination. However, such interactions do not occur in a vacuum and cannot be simply attributed to individual medical staff; they are in fact mediated by a number of meso-[217] and macro-level factors which are shaped by wider influences of social norms and structures, including hierarchical power structures within health services, structural inequalities, institutional racism and sexism (Bohren et al., 2015; Rubashkin and Minckas, 2018: 238). This is demonstrated in each of stories presented in this study; while Traveller women recognised that their negative interpersonal experiences with health services were

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[216] Forced sterilisation policies in Europe have been implemented in Austria, Canada, the Czech Republic, Denmark, Finland, France, Germany, Norway, Slovakia, Sweden, and Switzerland. According to Albert and Szilvasi (2017:3), of those countries, Austria, Germany, Sweden, Norway, and Switzerland have assumed responsibility for such policies, enacting special measures for victims, as have the U.S states of North Carolina and Virginia, with legislation pending in California.

[217] Bowser and Hill (2010) identify underlying factors that shape abuse of health care providers, specifically provider demoralization related to weak health systems and shortage of human resources and professional development opportunities .

fundamentally ‘wrong’, they also highlight their lack of autonomy and agency in these spaces (Martin, 1984) as a result of their gender and ethnicity.

Traveller women’s stories have pointed to serious questions in both policy and mainstream services, with the most concerning aspects of these stories reflected in women’s examples of explicit abuse and disrespect. While other jurisdictions have enacted progressive legislation to combat obstetric violence, Ireland’s approach to women’s reproductive and maternal health policy has provided the necessary legislative grounding for this to occur, effectively sanctioning such behaviour in clinical settings. As noted in Chapter 2, Article 40.3.3° of the Eighth Amendment in the Irish Constitution effectively suspends a woman’s right to bodily autonomy during pregnancy and childbirth. The Eighth Amendment provides that the right to life of the “unborn” must be respected, defended and vindicated “with due regard to the equal right to life of the mother” (Government of Ireland, 1937). The rationale for the insertion of the Amendment to the Constitution was to uphold both women and foetal rights equally. Although clinicians have been using the Eighth Amendment in guiding their clinical practice since 1983, it wasn’t until relatively recently that the HSE developed its official National Consent Policy (2017b: 41) which explicitly refers to the ambiguity surrounding a woman’s right to refuse treatment, including procedures that she deems unsafe and inappropriate as reflected in Rosie’s story. Both the Eighth Amendment and the HSE National Consent Policy presents key obstacles in ensuring a women’s right to health is respected, protected and fulfilled.

However, as discussed in Chapter 2, the recent referendum on the Eighth Amendment raises key questions in this regard as it has clear consequences for the delivery of maternity services in Ireland, and in particular, the rights of pregnant women in obstetrical settings. The change in the law suggests serious implications for HSE National Consent Policy and professional protocols on what is considered appropriate interventions in this regard. However, it is not clear how this will be translated into practice as health services contend with a number of complex structural issues as outlined in the sections above. Further, as evidenced in Chapter 2, given the track record to date on policy implementation it remains to be seen how this will yield more positive outcomes for women, including Traveller women.

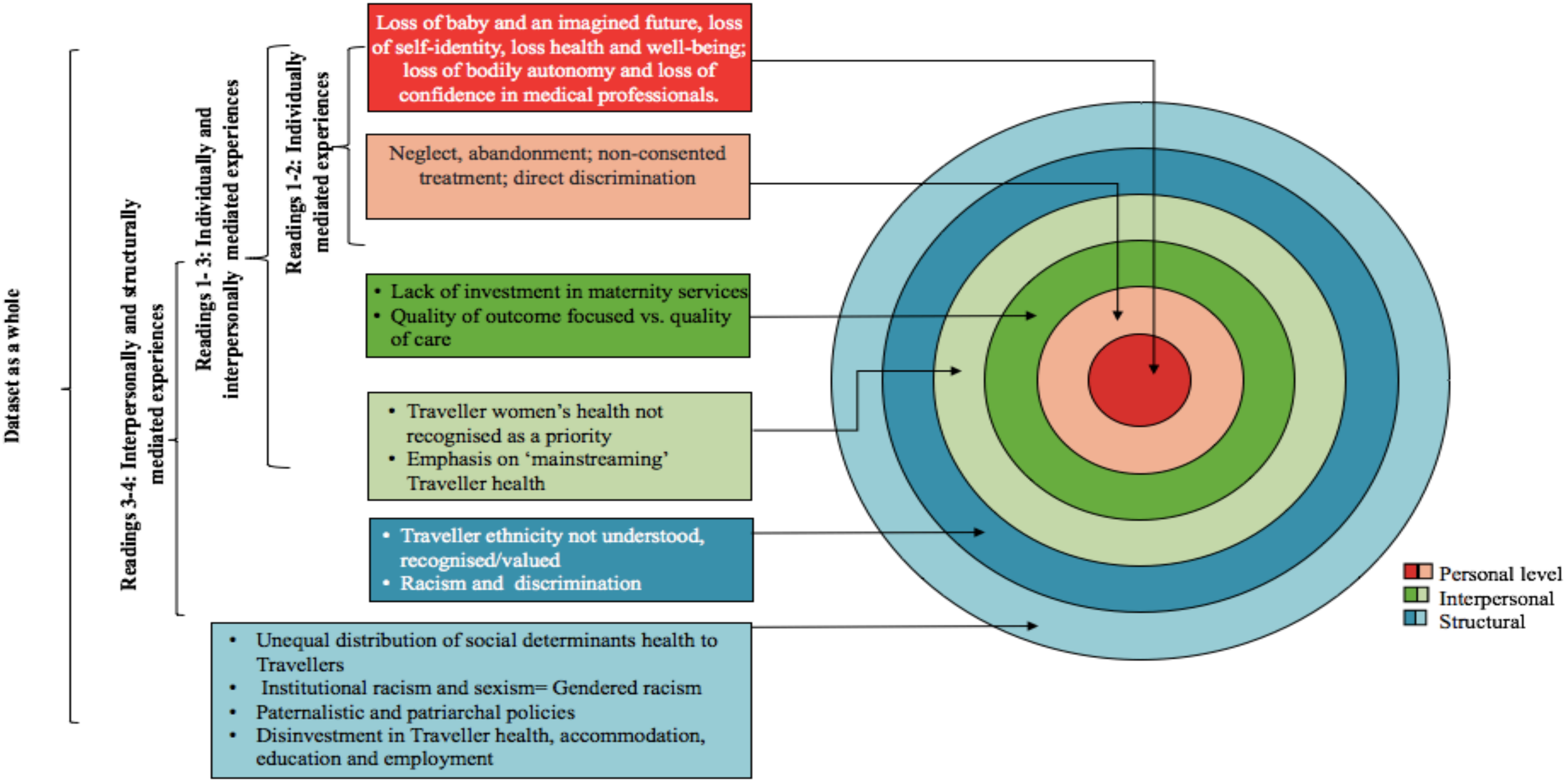

Figure 5: Traveller women's experiences of pregnancy loss in Ireland: personal, interpersonal and structural analysis

8.9 The voice-centred relational method and its contribution to a new understanding of Traveller women's lived experiences

This study makes a distinct contribution to the scholarship on gendered racism and discrimination as it relates to minority ethnic women. It contributes to the small body of qualitative research on pregnancy loss and provides a unique understanding of minority ethnic women's experiences in the regard. It has also made a number of theoretical, methodological and applied contributions.

8.9.1 Contributions to substantive and theoretical scholarship

In terms of the small body of literature on both Traveller women and pregnancy loss this study has made several contributions. First, in the absence of scholarly attention to Traveller women's lives, this study contributes to a new understanding of Traveller women's lived experiences by illuminating the ways in which pregnancy losses are experienced on a number of levels – individually, interpersonally and structurally. It moves away from previous individualised readings of loss and instead locates them within the social and culture milieu in which women live, including broader experiences of gendered racism. This provides a unique perspective in which to understand Traveller women's experiences of maternity services and some of the key barriers which restricts Traveller women's equality of access, participation and outcomes both at a policy and a health service level.

Second, the study adopts a unique theoretical framework by using structural violence and intersectional theory to provide a holistic representation of Traveller women's experiences as felt on micro, meso and macro levels. It is the first of its kind to use the concept of racialized obstetric violence as an analytical tool in understanding Traveller women's experiences of pregnancy, childbirth and loss. It also contributes to the global body of literature on obstetric violence and provides a new dimension through loss. Third, this study has added to social science scholarship on pregnancy loss by providing a new perspective on the ways in which intersectional identities, including gender, ethnicity, age and marital status shape women's experiences of pregnancy loss.

8.9.2 Methodological contributions

This study has also made methodological contributions in ensuring an overall participatory approach throughout the research process and in its endeavour to ensure reflexivity and accountability. As McDonagh writes, power differentials in research do not simply dissipate just because a feminist approach is used, nor does it ensure anti-racist content or ideology, as power between the researcher and the researched is “balanced in favour of the researcher, for it is she who eventually walks away” (Stacey, 1991; Cotterill, 1992: 604; Reinharz, 1992; Wolf, 1996; McDonagh, 2000; Mauthner and Doucet, 2006: 30). I am both deeply committed and invested in the work of Pavee Point and its mission to promote equality and human rights through a community development approach. These are the core values that underpin my work both as a researcher and professional. I believe that by working in solidarity and in partnership, research can be used as a vehicle to promote human rights, social justice and equality. The approach taken to this study is distinctive as it worked in solidarity with Traveller women and Traveller organisations. It provided added value in terms of the development and scope of the research while at the same time directly informed Pavee Point’s work on an ongoing basis including policy work. It also had a practical dimension as emerging findings have been used throughout the research process and are continuing to be used in informing and shaping the work on a local, regional and national basis.

Furthermore, in an attempt to ensure an epistemological multiplicity of Traveller women’s voices were placed at the crux of the research process, an innovative methodology was required. The BNIM style interview created the necessary conditions for Traveller women to tell their stories within their established parameters and without interruption. This was integral to the research process and to operationalising a participatory approach to the project. Traveller women’s voices have been constrained and silenced within academic scholarship and in policy as discussed in chapters 1 and 3. While the BNIM influenced interviews focused on Traveller women’s personal and interpersonal narratives, the VCR method took this one step further by illuminating the structural dimensions of Traveller women’s narratives, providing a clear link between all three, by locating the individual stories within grand or macro-level narratives (Benhabib, 1995: 354). The VCR method requires the researcher to confront her own biography and subjectivities in order to effectively demonstrate reflexivity. A focus on my own story was essential in order to confront and acknowledge my positionality as a non-Traveller woman. This moves interpretation about Traveller women's lives from an *implicit* process to an *explicit* process, making 'conventions of interpretation clear' (Brown et al., 1991: 41).

8.9.3 Methodological limitations

A small sample size in any type of research poses considerable questions around participant privacy and anonymity. The methodological approach to this study, in particular, the use of the VCR method and the development of case studies present additional challenges. Given its relatively small population and particularities to each case, Traveller women in this study could potentially be identified. I sought to mitigate this by presenting women's stories as poems and ensuring that identifying information was minimised in the overall collective narratives presented. I also removed, where relevant, any explicit reference to the gender of Traveller women's children as this could inadvertently lead to identification. As a result, where gender was referenced by women, I replaced with the terms 'child' and 'baby.' It was imperative to ensure an ethical research practice as my obligation to participants supersedes "the goal of gaining new knowledge through research" (Maynooth University, 2016: 7).

Moreover, as outlined in Chapter 5, one of the key challenges for using the VCR method is the amount of time dedicated to data analysis, particularly in the development of case studies. As Mauthner and Doucet (2011) highlight, the detailed and time-consuming work was valuable for understanding the depth and complexity of Traveller women's experiences, but I was conscious that I was not spending as much time on each woman's interview. Similar to Mauthner and Doucet (2011: 132), I felt like I was 'short-changing' many of them and felt that I was missing out on understanding and knowing every Traveller women's story as intimately as those of Rosie, Megan and Catherine.

8.9.4 Applied contributions: connecting research to practice

When I initially set out on this 'research journey' I was caught off-guard by a colleague who candidly queried, "what difference will this research make to Traveller women, anyways?" I vaguely remember mumbling something about contribution to knowledge and informing policy and practice before quickly exiting the conversation. Her question echoed concerns from Travellers and Traveller organisations on the usefulness of academic research and it exposed some of the internal tensions which I was feeling at the time which were: how could this study potentially inform policy? How could it inform practice? How could it inform the work of Traveller organisations and effectively, what value is this study if it doesn't, in some, way affect positive change in Traveller women's lives? Over the past four years, I have returned to this question, bearing in mind each of the interviews with Traveller women and in countless stories I have listened to from other Traveller women. In both instances, Traveller women identified the lack of clear and accessible information for women during and after loss. Working with the PHCTP in Pavee Point, we secured a grant and developed a national Traveller perinatal health initiative, *Pavee Mothers* in parallel with the PhD research. A key dimension to this initiative was the development of an accessible perinatal information pack which includes specific information on pregnancy loss and mental health, as identified by Traveller women in this study. The pack is visual and not contingent on literacy levels. This is complimented by an online equivalent which includes an audio function which reads out the information. All images and recordings are of and by Traveller women. The finalised content was developed in consultation with maternity services and other PHCTPs across the country. Although the initiative is Traveller specific, it is transferable and can be used by other women (and men), including Roma women.

While I am not under any illusion that *Pavee Mothers* is the panacea for addressing all of the key issues outlined in this study, it is one practical tool borne out of this study. In doing so, it addresses a clear gap for Traveller women in accessing health information. At the same time, it also builds awareness amongst key stakeholders, specifically services providers, about the particular barriers Traveller women experience in using their services. The initiative provides a platform from which further work can be developed, including policy development in the broader context of overhauls in the national maternity services.

8.10 Conclusion

This chapter has focused on Traveller women's experiences of pregnancy loss in relation to the literature reviewed in previous chapters and has outlined how women experience loss on an individual, interpersonal and structural levels. On an individual level, Traveller women experience pregnancy loss as a traumatic life event, eliciting intense physical and emotional pain, sadness, distress and grief. Evidence from this study suggests that women experience pregnancy loss as a traumatic event for the following two reasons: (1) Traveller women conceptualise this event as the death of their child; and (2) they encounter various barriers in engaging with health services, including the negative ways in which they recall being treated by health services during and after their loss. On an interpersonal level, Traveller women identify three types of relationships: (1) intimate relationships (familial); (2) relationships with

Traveller Community Health Workers (CHWs) and Primary Health Care for Traveller Project (PHCTPs) (professional/familial and personal); (3) and institutional relationships (institutional actors and health services). Traveller women present these relationships in stark contrast to one another with institutional relationships presented as uncaring and unsupportive and intimate and in-between relationships as caring and supportive. Institutional relationships are placed at the centre of Traveller women's overall narratives and it is in this context that Traveller women identify neglect, abandonment, non-consented treatment and discrimination as key components in their overall engagement with health services and broader pregnancy loss experiences.

This study suggests that Traveller women's structural experiences of pregnancy loss are mediated by paternalistic, patriarchal and racist policies which are manifested both covertly and overtly in the Traveller women's lives. These mechanisms can be analysed as forms of structural violence or invisible manifestations of violence that are built into the fabric of society, producing and reproducing Traveller inequalities (Farmer, 2004). However, given obstetric dimension of women's experiences in this regard, obstetric violence is a useful lens for understanding Traveller women's experiences of both structural and interpersonal violence within obstetric settings.

Chapter 9

Conclusion: Traveller women's experience of pregnancy loss - a case of racialized obstetric violence

9.1 Introduction

This study is an exploration of Traveller women's experience of pregnancy loss. It examines the individual, interpersonal and structural factors that mediate Traveller women's experiences. This study suggests that the broader structural landscape of discrimination, racism, sexism, marginalisation and inequality is integral to understanding Traveller women's lived experiences, including pregnancy loss. It highlights Traveller women's experiences of disrespectful and abusive treatment by health services during and after pregnancy loss; this includes neglect, abandonment, non-consented treatment and discrimination. It argues that Traveller women's experiences of pregnancy loss are shaped and pronounced by gendered racism and suggests that these experiences are racialized obstetric violence on the basis of gender and ethnicity.

This study has demonstrated that Traveller women's experiences are not unique within the Irish context, but the gendered racialization and devaluation of Traveller women by the State has resulted in starkly different realities and experiences for Traveller women than for the general population. The study used an intersectional lens to highlight the particularities of Traveller women's experiences and illuminated the ways in which minority ethnic women's experiences of obstetric violence are racialized. It has argued that racism and discrimination on the basis of gender and ethnicity has been normalised globally, and as a result, instances of mistreatment in maternity settings have become overlooked or accepted by institutional actors, health practitioners, as well as indigenous and minority ethnic women themselves.

In this final chapter, I provide a brief outline of the key findings summarising what they revealed and discuss their implications for minority ethnic women, including Traveller women. I reflect on some of the strengths and limitations of this research, in addition to the original contribution of this research. I also reflect on the overall approach of this research and review what I have learned from the process. Lastly, I make recommendations for future research and policy.

9.2 Research question, aims and objectives

The central research question of this study was to explore Traveller women's experience of pregnancy loss in Ireland. The objectives of the research were to explore:

- The personal, interpersonal and structural factors that mediate Traveller experiences of pregnancy loss; and
- the voice-centred relational (VCR) method and its contribution to a new understanding of Traveller women's' lived experiences

The aims of the dissertation were twofold: (1) to develop a holistic understanding of Traveller women's experiences of pregnancy loss; and (2) to develop an assessment of the voice -centred relational (VCR) method as a response to the above research questions.

9.3 Theoretical approaches and research design

This study assumed an interpretivist, relational, voice-centred, feminist methodology which understands knowledge socially as situated, taking Traveller women's direct experience as the basis for knowledge. In doing so, it recognises that Traveller women's experiences do not occur within a vacuum, but are embedded in a complex web of larger social and structural relationships (Gilligan, 1993[1982]; Mauthner and Doucet, 1998a; Gilligan et al., 2006). The specific methods used were BNIM-influenced participant structured interviews with eleven Traveller women and using a voice-centred analysis approach to analyse interviews. BNIM interviewing was a useful method for this study as it created the necessary conditions:

1. for Traveller women to articulate experiences through their own terms without being 'suppressed' or 'micro-managed' by the researcher (McDonagh, 2000; Wengraf, 2001);
2. to attend to Traveller women's lived experiences on both individual and collective levels;
3. in providing a clear framework for locating and tracing women's experiences within the broader structural context; and
4. in providing a clear systematic approach to conducting interviews

More importantly, using a BNIM-influenced participant structured interview complimented the VCR method as both provide a framework for 'situated subjectivity' by locating and linking Traveller women's experiences across micro, meso and macro levels. This facilitates a rich and holistic analysis of women's experiences by placing them, as McDonagh (2000) notes, at the 'centre' (Mauthner and Doucet, 1998b; Chamberlayne and King, 2000; Wengraf, 2001, 2012; Chamberlayne and Rustin, 2002). Aligning with the broader epistemological and ontological positioning of the study, both approaches directly responded to the overall research question, aims and objectives. Lastly, both provide pragmatic methods to operationalise reflexivity which is a key principle of this study.

9.4 The operationalisation of racialized obstetric violence on individual, interpersonal and structural levels

This research is concerned with Traveller women's pregnancy loss experiences as specific manifestations of the intersecting gendered and ethnic locations of the study group within maternity care services. It makes a key contribution to advancing knowledge about the ways in which racialized obstetric violence is operationalised at individual, interpersonal and structural levels.

On an individual level, obstetric violence is demonstrated through Traveller women's stories of constraint, distress, mistreatment and trauma**.** These stories reflect individual experiences of neglect; abandonment; non-consented treatment; and discrimination as detailed and discussed in chapters 7 and 8. While these experiences were recognised as fundamentally wrong by participants, they were also understood and evidenced through this research as routine practices of obstetric treatment, indicating that practices were sanctioned, normalised and institutionalised. While similar experiences have been documented in the treatment of women in obstetric settings globally, including Ireland,[218] Traveller women's particular experiences are distinct as they reflect various forms of anti-Traveller racism (Helleiner, 2000[1961]); McDonagh, 2013, 2017; Collins, 2017b; Fay, 2018). These distinct experiences are contextualised throughout Traveller women's stories, particularly in relation to racial micro-aggressions displayed by health staff and Traveller women's feelings of racialized hyper visibility within institutions as discussed in Chapter 8. Such experiences are further demonstrated in findings of the lack of 'culturally appropriate' service provision, the specificity of neglect and abandonment for Traveller women *during* labour and *after* loss, and the racialized particularity of fears of children being 'taken into care'. The findings of this study emphasise the importance of recognising that interpersonal manifestations of obstetric violence are inherently bound up with the individual and structural level. This includes the medicalisation of childbirth and obstetric authoritarianism;[219] the paradox of 'safe birth;'[220]

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[218] See chapters 2 and 4 for further discussion
[219] See Chapter 4, Section 4.3
[220] See Chapter 8, Section 8.6

the 'poverty' of maternity service provision and poor working conditions for health professionals.[221]

9.5 Connecting the individual, interpersonal and structural

Furthermore, this study reflects the ways in which obstetric violence is operationalised on structural levels. It argues that women's experiences of pregnancy loss are mediated and shaped by the social, historical, political and structural contexts in which they are located. Systemic failures at structural (policy and service provision levels) have contributed to the normalisation of obstetric violence. However, it posits that such interactions do not occur in a vacuum and cannot be attributed to individual health professionals. Concurring with Jewkes and Penn-Kekana (2015) and Sadler et al., (2016), this study contends there is a need to avoid placing blame on health workers as a group, and instead, suggests further consideration of the material conditions and socially constructed symbolic meanings which create the context for obstetric violence to occur and to become normalised. This includes broader influences, internal beliefs, rules and practices, which respond to and reproduces particular ideologies of gender and ethnicity, across health services and other institutions (Bohren et al., 2015; Rubashkin and Minckas, 2018: 238). It is reflected in the dominant discourse of 'culture-based frameworks' (Farmer, 2003: 2004) an overemphasis on minority ethnic women's agency and 'personal responsibility' in shaping perinatal outcomes. As Sadler et al. (2016) argues, the acceptance of such practices implies the consent of both health services and women within a social relationship where the knowledge shared amongst all actors only allows the framing of the violence itself as if it were a sanctioned, normalised and an institutionalised practice. Therefore, violence is not only accepted, but also reproduced and reinforced by all actors involved including women, families, professionals, health services and the State. It is in this context that obstetric violence reinforces both gendered and racialized narratives in maternity policy and services and services.

9.6 Coming to understand racialized obstetric violence

This understanding engenders a critique of the emerging literature on obstetric violence which has been framed as a consequence of structural violence and gender inequality. This study suggests that these concepts do not adequately account for the racialized experiences reflected in Traveller women's pregnancy loss narratives. Traveller women's individual and collective

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[221] See Chapter 7, Section 7.1.4 and Chapter 8, Section 8.7

narratives reflect that particular contours of racism materialise in their interactions with health services and other institutions. These experiences are informed by mutually constituting factors of social location and structural disadvantage which is predicated on the intersection of ethnicity and gender and the negative outcomes of the two, racism and sexism (Collins, 1990; Crenshaw, 1991, 1997; Essed, 1991, 2001;). Traveller women's collective experiences of differential treatment and material conditions are rooted in structural racism, and in particular, in a shared history of sexism, oppression and assimilation.

The findings from this study reflect a number of parallels evident in international scholarship documenting indigenous and minority ethnic women's experiences of mistreatment and abuse in obstetric settings (see chapters 4 and 8). This literature suggests that even when indigenous and minority ethnic women have equality of access to health services, the quality of service is perceived as inadequate and substandard when compared to women in the majority population, with racism as a key factor shaping minority women's experiences (Janevic et al., 2011; Pohjolainen, 2014; Janevic et al., 2017; Watson and Downe, 2017: 1). Therefore, this study makes a new contribution to knowledge, as it argues that women are not homogenous, and gender is not the only conceptual lens to understand obstetric violence. An intersectional analysis of racism, class and gender subordination is crucial in understanding how manifestations of obstetric violence are racialized and experienced by Traveller women and other minority ethnic women on individual, interpersonal and structural collective levels.

Moreover, this study suggests that racialized obstetric violence is a distinct form of obstetric violence, which demands a distinct analysis. Agreeing with Sadler et al. (2015), obstetric violence is a feminist issue, reflecting gender-based violence, but it also reflects a particular form of gender violence on the basis of ethnicity. Obstetric violence has disproportionally affected marginalised women, specifically indigenous and minority ethnic women, all of whom share a collective history of systematic mistreatment and abuse in obstetric settings as discussed in Chapter 4.

This domination has become inscribed both *on* and *in* women's bodies, leaving physical traces left by centuries of domination, assimilation segregation, and stigma (Farmer, 2004; Fassin, 2011b; 429). Racialized obstetric violence suggests that structural violence and structural racism coalesce during the perinatal period and manifests itself in explicitly harmful consequences for minority ethnic women, including gendered racial health inequalities. Such disparities are indicative of stratified reproduction in that the inequalities of ethnicity, as well as class, gender, culture, and status, produce differential reproductive outcomes (Davis, 2003; Washington, 2006; Chinyere-Oparah et al., 2015; Chadwick, 2018). This includes disproportionately poorer perinatal outcomes for minority women, including higher rates of infant/maternity mortality and morbidity for indigenous and minority ethnic women.[222]

This study argues that the consideration of gender as the only defining feature of obstetric violence is limited in its explanatory power. Instead, it suggests that it is crucial to build on and expand on this analysis to include a focus on the coalescing of various ‘axes’ (Crenshaw, 1991, 1997) of social location, including ethnicity. This leads us to: how can this expanded analysis be used to better understand the experiences of minority ethnic women? First, it acknowledges the distinct racialized experiences of Traveller women and minority ethnic women within obstetric settings and frames women’s experiences of disrespect and mistreatment as racialized obstetric violence. This provides a better conceptual understanding of the nuances and complexities of women’s experiences and the interaction between micro-level narratives and macro-level processes and structures. It is within this context that we can begin to shift away from rooting our analysis at the individual level and constraining our understanding of minority ethnic women and Traveller women’s experiences to the lens of gender. Second, it suggests that through this framing we can better problematize these practices which have been hidden, invisible and normalised. We can also identify these intersectional experiences and inequalities of outcome which have been shaped by broader cultural and ideological factors and use this to inform strategic and holistic responses in both policy and service level provision.

This study therefore makes a key contribution to advancing knowledge about the personal, interpersonal and structural factors which mediate Traveller women experiences of pregnancy loss. Additionally, it has provided a framework for understanding how we can explore and contextualise minority ethnic women’s experiences of pregnancy loss. In doing so, it demonstrates that various ways in which intersectional forms of structural violence seep into institutions, creating the conditions in which disrespect, mistreatment and abuse are *felt* on individual and interpersonal levels.

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[222] See chapters 1 and 4

9.7 Reflections on methodological approach

The VCR method provided a number of key benefits for this study as it placed Traveller women's narratives at the centre of analysis. It also supported the *hearing* of Traveller women's voice in a new way. In doing so, it facilitated the uncovering the multiple layers-individual, interpersonal structural layers of women's stories. It is also provided a clear framework in which to explore these layers in further detail, specifically, the broader historical, social, policy and structural contexts in which shape women's felt experiences of pregnancy loss. Overall, the VCR method facilitated a holistic analysis of Traveller women's stories by bringing together the micro, meso and macro processes. One challenge of the method, however, is the amount of time dedicated to a very small number of cases as reflected in this study and the fact that not all participants are given equal attention in this regard.

9.8 Recommendations

This study has identified clear gaps in research and policy, with Traveller women remaining marginalised between the two. As McDonagh (2000) notes, Traveller women's experiences are not privileged epistemologically in either realm and thus they remain excluded. In this regard, I have identified some key recommendations that could have potential positive outcomes for Traveller women based on my experience in this research project and my ongoing work with Pavee Point:

9.8.1 Research

A number of key findings in this study merits further consideration for research, this includes minority ethnic women's experiences of perinatal mental health; intergenerational pregnancy loss; and the impact of pregnancy loss on minority ethnic men. However, while there is clear potential to carry out further research to explore these issues and much broader issues in relation to Traveller health inequalities as outlined in the AITHS, the chief recommendation from this research is not simply the substantive issue, but rather, agreeing with McDonagh (2000) that the methodological approach is imperative. This includes ensuring methodological and epistemological accountability as discussed in Chapter 5. This research reflects the value of narrative in achieving those outcomes, while at the same time, it demonstrates the importance of embedding an active participatory approach throughout the research process.

9.8.2 Policy

This study has provided a comprehensive discussion on Traveller related policy in Ireland and has argued that while effective policies have been developed in partnership with Travellers and Traveller organisations, poor implementation has hampered substantial progress. It is clear that in the absence of implementation, any recommendations for policy will be fruitless. However, there is ample opportunity to address this given the current development of the National Traveller Health Action Plan as discussed in Chapter 3. This will be the roadmap for Traveller health over the next number of years. Therefore, its implementation will be key to addressing Traveller health inequalities and the issues identified in this study. However, in the absence of clear dedicated budgets, impact indicators, timelines, dedicated resources and key drivers, the plan will be, as Fay (2018) argues, "effectively doomed from the outset' (7). Therefore, it is in this context that the study recommends the publication and implementation of a National Traveller Health Action Plan, including the establishment of a Planning Advisory Body for Traveller Health (PATH) with dedicated resources to ensure delivery and implementation.

Furthermore, notwithstanding the clear lack of policy implementation in relation to Travellers, this study also highlights the lack of implementation of maternity policy in Ireland. It also identifies clear gaps in existing maternity policy in relation to minority ethnic women, including Traveller women. As discussed in Chapter 2, Ireland is at a critical juncture with a number of overhauls in legislation and policy which has clear implications for service provision. The needs of minority ethnic women, including Traveller women, must be considered in this regard. Traveller organisations and other organisations working in partnership with minority ethnic women are a valuable asset and must be consulted throughout the development processes and in overseeing implementation.

In addition, this study argues that only addressing the micro- and meso-level *symptoms* of obstetric violence will not yield in any substantial collective change for women. Rather, it is only through tackling the structural dimensions of obstetric violence that macro-level *causes* can begin to be addressed. This includes acknowledging and reframing practices detailed in this study for what they are: obstetric violence. In shifting our analysis, we can begin to strategically tackle obstetric violence and move towards developing innovate policy solutions rooted within a human rights framework.

9.9 Conclusion

This research is not simply about loss; loss is one particular dimension of Traveller women's lived experience and one particular story in which they were willing to share with me for the purpose of this research. Traveller women live with loss every day; with loss wrapping itself around the entire community through high infant mortality rates, high suicide rates, lower life expectancy and higher rates of mortality at all stages of the life course (AITHS Team, 2010a) (See Appendices I-VII). This research is about the ways in which intersectional forms of structural violence seep into institutions, creating the conditions in which disrespect, mistreatment and abuse are *felt* by Traveller women. As Farmer (2005: 8) reminds us, structural violence "does not involve bullets, knives, or implements of torture," but rather, it is "structured by historically given processes and forces that conspire to constrain agency" (Farmer, 2005: 40). The normalisation of such practices reflects the embedded nature of racism, sexism and discrimination within social structures, making it appear normal and part of the everyday experience. However, Traveller women, through their stories, force us to look 'sideways' (Žižek, 2008) at macro-level processes which allow violence to materialise as hidden. This has been facilitated through the relationship between the approach to data collection and analysis, with BNIM interviews illuminating Traveller women's personal and *felt* experiences and the VCR method providing a clear framework in linking those micro-level experiences to the macro-level processes and structures. It from this context that we come to both *hear* and *understand* Traveller women's stories in a different way.

Appendix I: Overview of Traveller health

AITHS Key Findings: Demographic Data

- 134 Excess Traveller deaths per year
- Life expectancy for Traveller men is 15.1 years and for Traveller women 11.5 years less than men/women in the general population
- Mortality is 3.5 times higher
- Infant mortality rate is 3.7 times higher
- Suicide rate among Travellers is 6.6 times higher than the general population
- Suicide accounts for a staggering 11% of all Traveller deaths
- Only 3% of Travellers found over the age of 65
- 42% of Travellers under 15 years of age compared with 21% of the general population
- Only 8 Travellers found over 85 years of age

AITHS Key Findings: Mental Health and Suicide

- 62.7% of Traveller women and 59.4% of Traveller men reported their mental health was not good for one or more days in the last 30 days, compared to 19.9% of the non-Travellers
- 56% of Travellers said that poor physical and mental health restricted their normal daily activities, compared to 24% of the non-Travellers
- Overall Traveller rate suicide is 6 times higher than settled population
- Suicide is 7 times higher for Traveller men and most common in young Traveller men aged 15-25
- Suicide accounts for approx. 11% of all Traveller deaths
- Suicide is 5 times higher for Traveller women

AITHS Key Findings: Discrimination

- 53% of Travellers “worried about experiencing unfair treatment” from health providers
- Over 40% of Travellers had a concern that they were not always treated with respect and dignity
- Over 50% of Travellers had concerns of the quality of care they received when they engaged with services
- 40% of Travellers experienced discrimination in accessing health services, compared to 17% of Black Americans and 14% of Latino Americans
- 66.7% of service providers who agreed that discrimination against Travellers occurs sometimes in their use of health services. Service providers also admitted that anti-Traveller discrimination and racism were evident within the services, resulting in substandard treatment of Traveller service users.

AITHS Key Findings: Trust in Health Services

- Traveller organisations and Primary Health Care for Traveller Projects (PHCTPs) were the most recognised and used support services for Travellers, particularly for mental health
- 83% of Travellers reported receiving health information and advice from PHCTPs
- The level of complete trust by Travellers in health professionals was only 41% compared with a trust level of 82% by the general population in health professionals

Source: AITHS Team (2010a)

Appendix II: Current Traveller health infrastructure

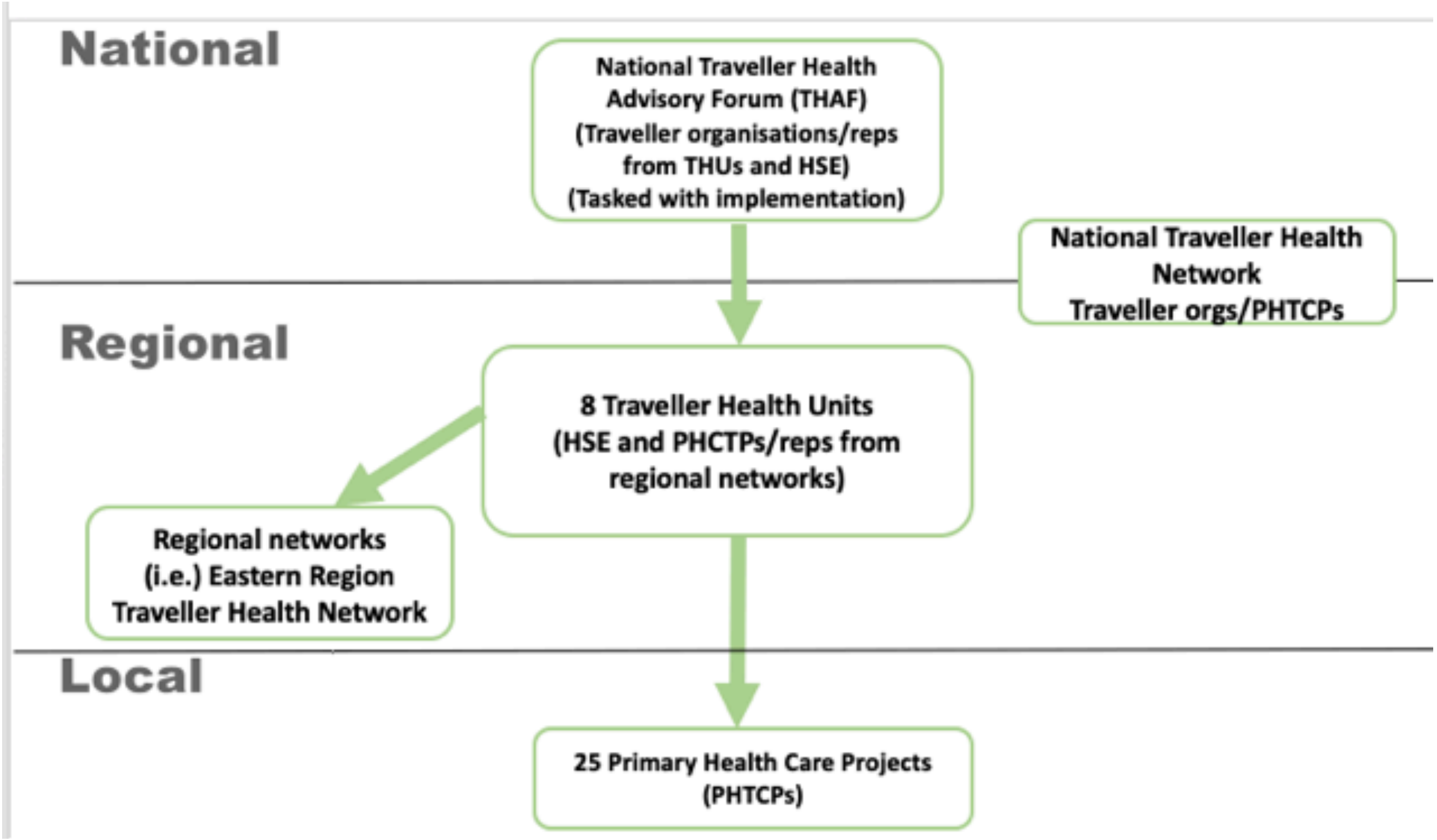
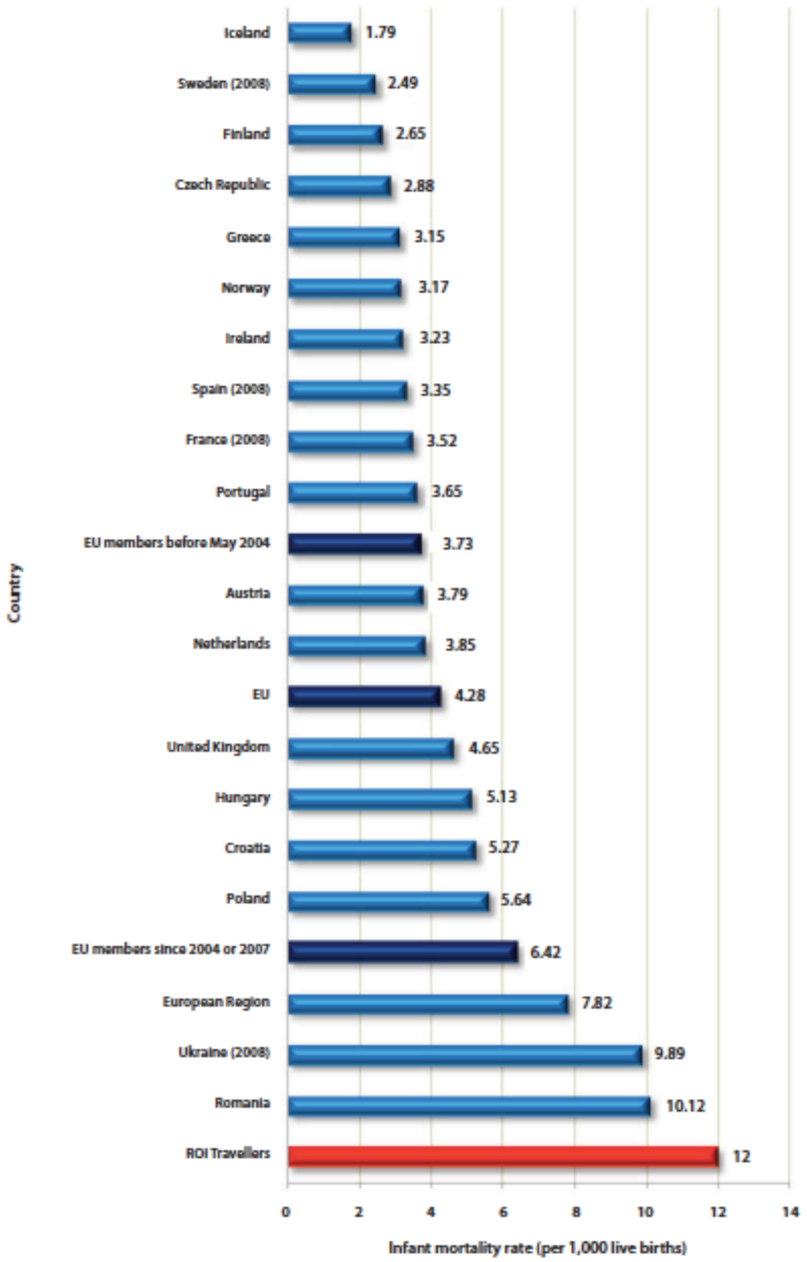


Figure 6: Current Traveller health infrastructure

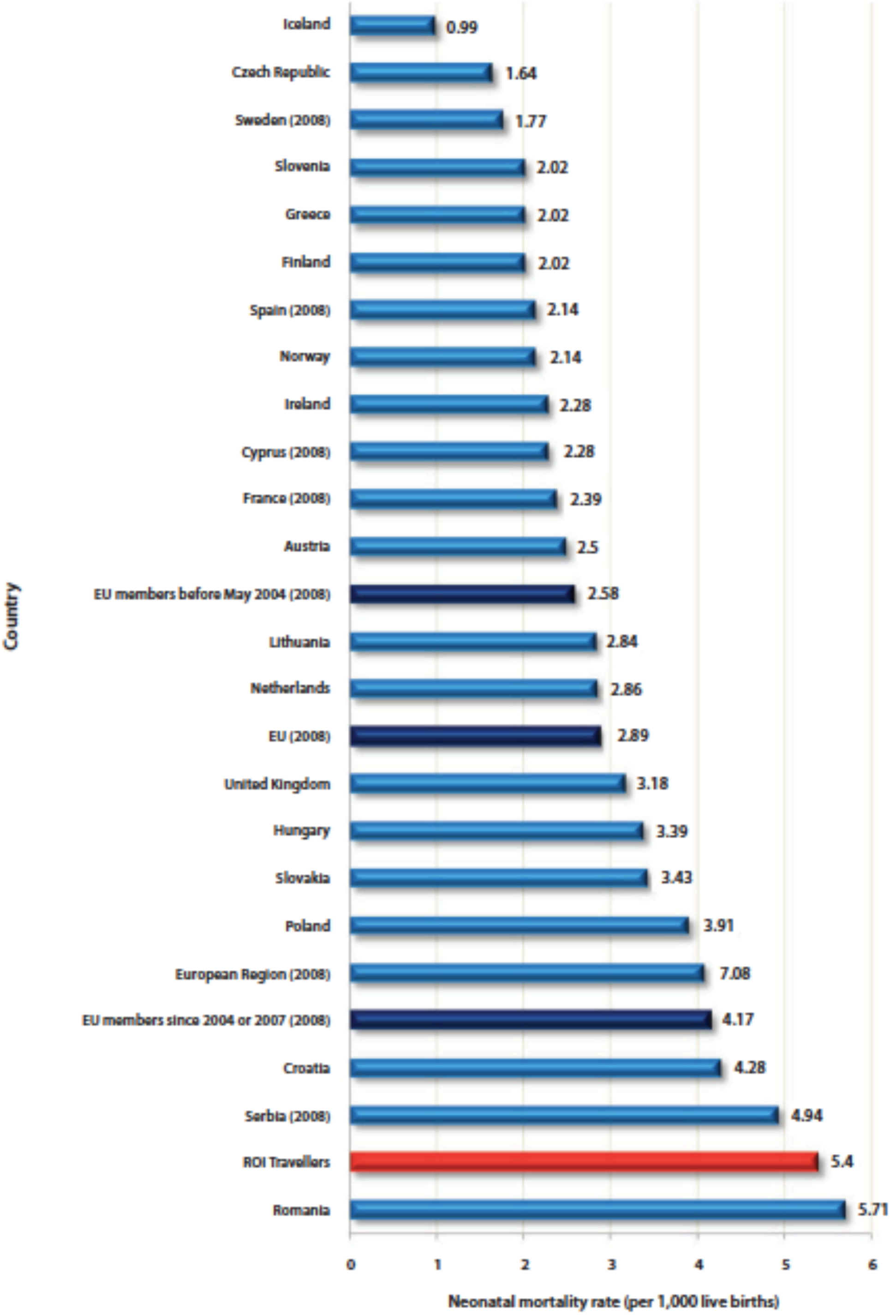
Appendix III: Infant mortality rate-Irish Travellers and Europe



Note: Countries selected based on availability of data and where appropriate and when 2008 data is used, it is noted in brackets after the country

Figure 7: Infant mortality rate-Irish Travellers and Europe (AITHS Team, 2010b)

Appendix IV: Neonatal mortality rate-Irish Travellers and Europe



Note: Countries selected based on availability of data and where appropriate when 2008 data is used, it is noted in brackets after the country

Source: World Health Organisation (2011)

Figure 8: Neonatal mortality rate-Irish Travellers and Europe (AITHS Team, 2010b)

Appendix V: Post-neonatal mortality rate-Irish Travellers and Europe

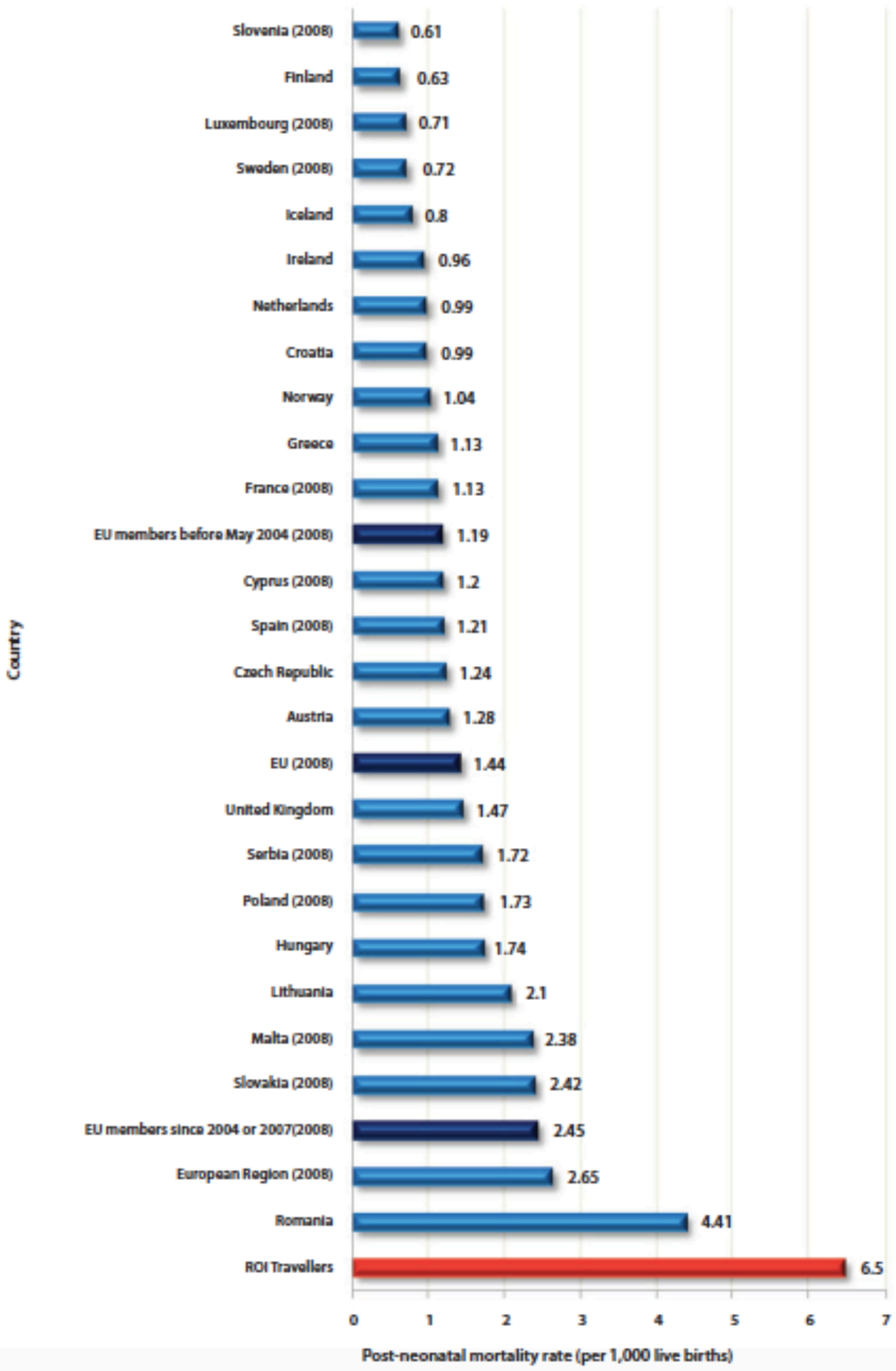
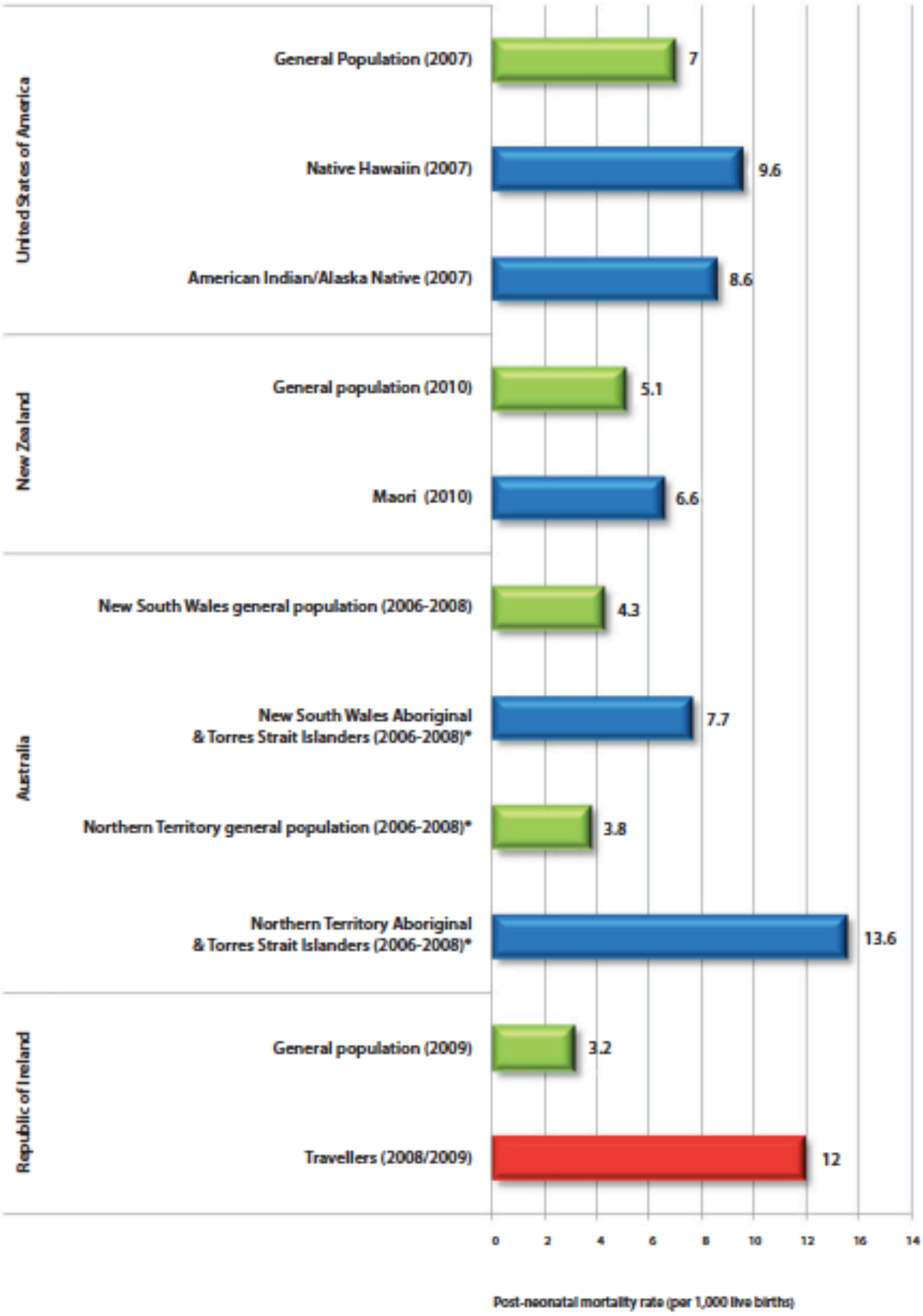


Figure 9: Post-neonatal mortality rate-Irish Travellers and Europe (AITHS Team, 2010b)

Appendix VI: Infant mortality rate- Irish Travellers, other minority ethnic groups and their respective majority population



*Australian infant mortality given according to New South Wales (NSW) and Northern Territory (NT) due to the large difference in Aboriginal and Torres Strait Islanders IMR, as reported by the Australian Bureau of Statistics (2010)

Sources: Australian Bureau of Statistics (2010), Statistics New Zealand (2010), Taualii (2009)

Figure 10: Infant mortality rate- Irish Travellers, other indigenous and minority ethnic groups and their respective majority population (AITHS Team, 2010b)

Appendix VII: Infant mortality rate- Irish Travellers and other minority ethnic groups

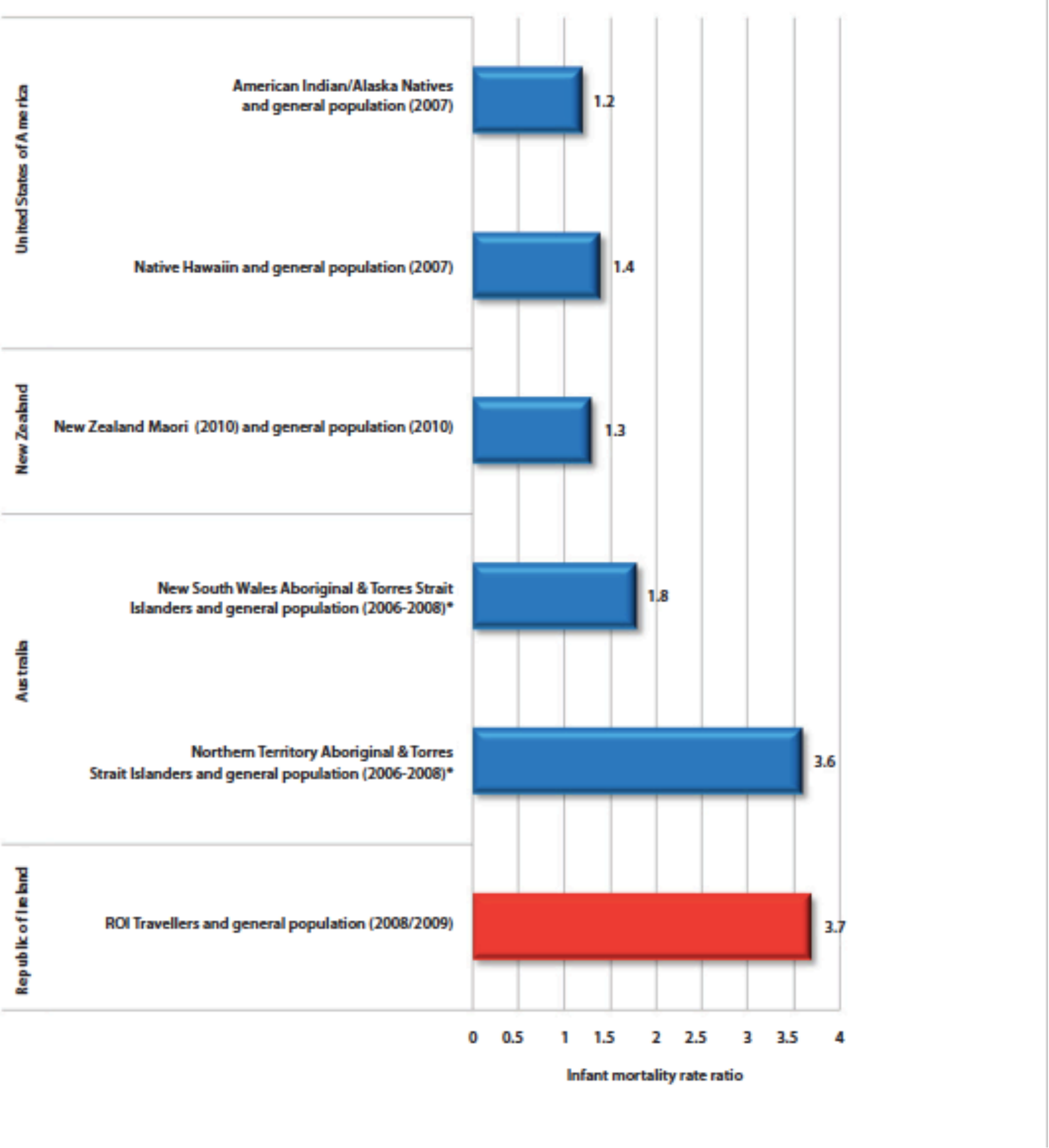


Figure 11: Infant mortality rate- Irish Travellers and other indigenous and minority ethnic groups (AITHS Team, 2010b)

Appendix VIII: Overview of Traveller policy structures

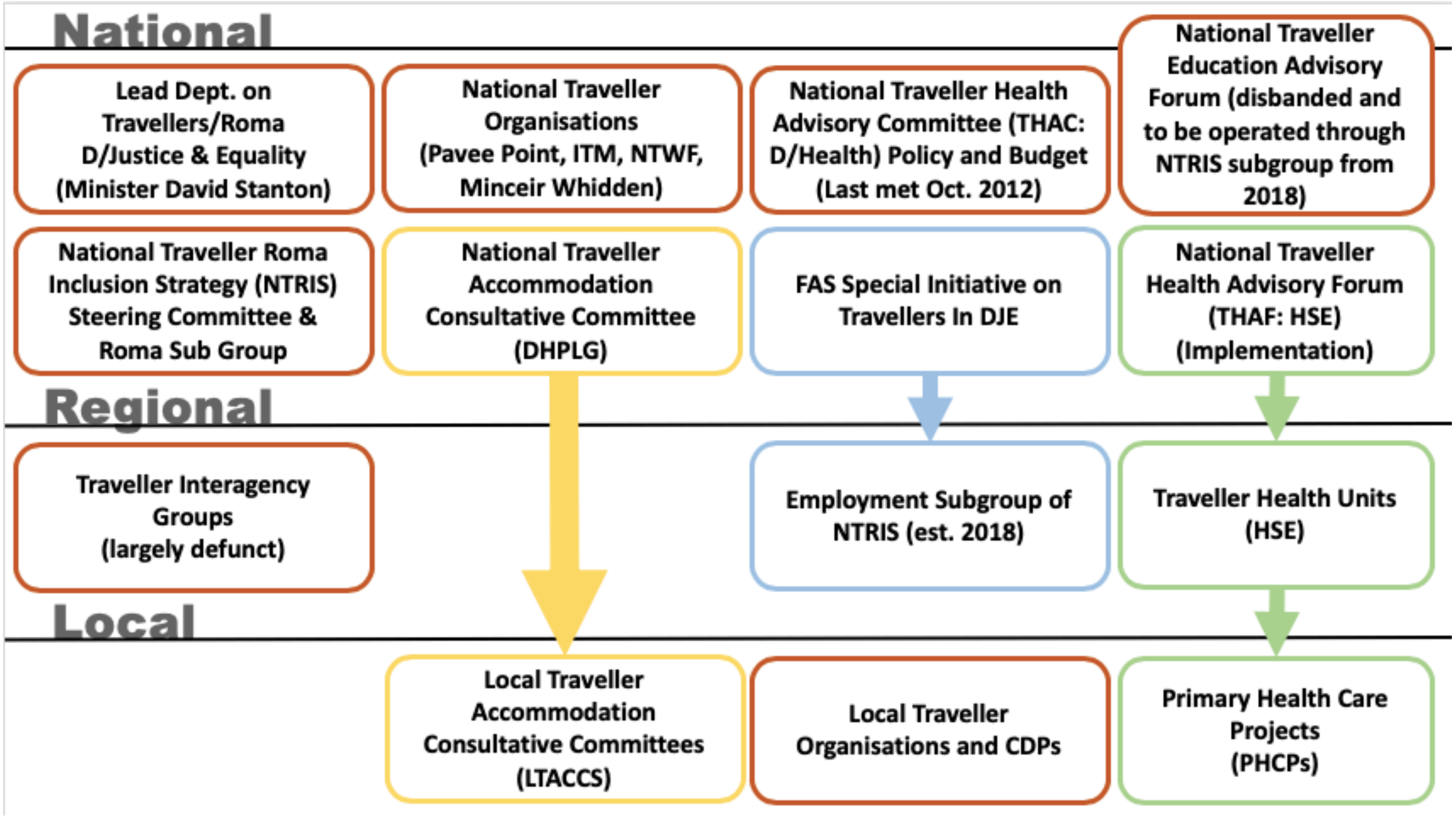


Figure 12: Overview of Traveller policy structures

Appendix IX: Classic SQUIN and the 3 (Sub)-sessions

A SQUIN: Single Question aimed at inducing Narrative(s)

> "Can you please tell me your life story,
> All the experiences and the events which were important for you,
> up to now,
>
> Start wherever you like
> Please take the time you need
> I'll listen first, I won't interrupt
> I'll just take some notes in case I have any further questions for
> after you've finished telling me about it all

Three Sub-Session Structure

ONE. Initial SQUIN - and initial response/account

- facilitation but no direction or interruption
- unspecified narrative questions if necessary
- note taking on topics for Sub-session 2

↓

TWO. Narrative Questions on Mentioned Topics only

- only topics raised in sub-session ONE
- only in the order of their raising
- only using the words used by the narrator

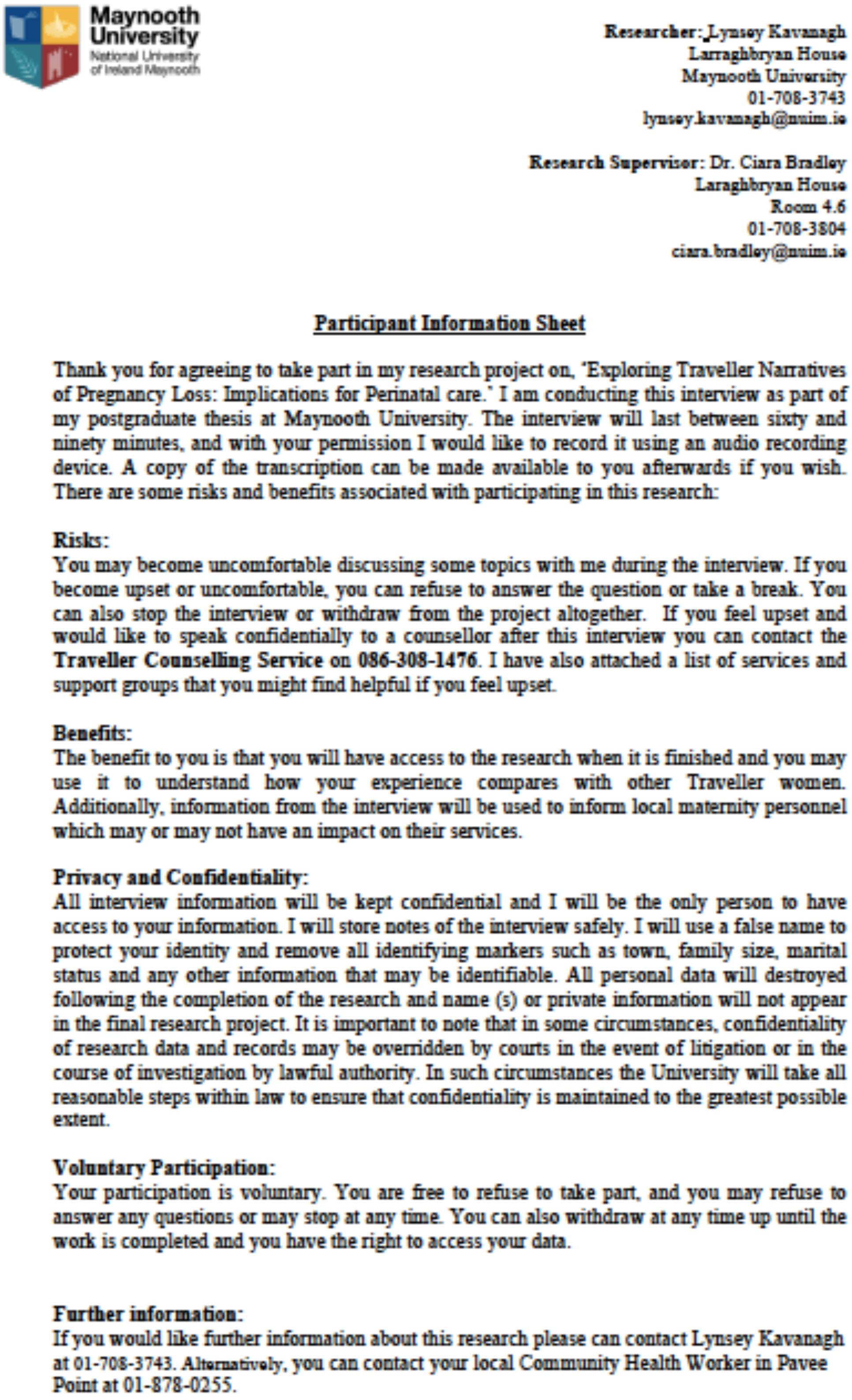
↓

maybe after analysis of material from ONE / TWO

THREE. All further questions relevant to the Interests and Theories of the Researcher

- some topics may arise from ONE or TWO
- others almost certainly won't

Appendix X: Research participant information sheet



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Participant Information Sheet

Thank you for agreeing to take part in my research project on, 'Exploring Traveller Narratives of Pregnancy Loss: Implications for Perinatal care.' I am conducting this interview as part of my postgraduate thesis at Maynooth University. The interview will last between sixty and ninety minutes, and with your permission I would like to record it using an audio recording device. A copy of the transcription can be made available to you afterwards if you wish. There are some risks and benefits associated with participating in this research:

Risks:
You may become uncomfortable discussing some topics with me during the interview. If you become upset or uncomfortable, you can refuse to answer the question or take a break. You can also stop the interview or withdraw from the project altogether. If you feel upset and would like to speak confidentially to a counsellor after this interview you can contact the **Traveller Counselling Service on 086-308-1476**. I have also attached a list of services and support groups that you might find helpful if you feel upset.

Benefits:
The benefit to you is that you will have access to the research when it is finished and you may use it to understand how your experience compares with other Traveller women. Additionally, information from the interview will be used to inform local maternity personnel which may or may not have an impact on their services.

Privacy and Confidentiality:
All interview information will be kept confidential and I will be the only person to have access to your information. I will store notes of the interview safely. I will use a false name to protect your identity and remove all identifying markers such as town, family size, marital status and any other information that may be identifiable. All personal data will destroyed following the completion of the research and name (s) or private information will not appear in the final research project. It is important to note that in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

Voluntary Participation:
Your participation is voluntary. You are free to refuse to take part, and you may refuse to answer any questions or may stop at any time. You can also withdraw at any time up until the work is completed and you have the right to access your data.

Further information:
If you would like further information about this research please can contact Lynsey Kavanagh at 01-708-3743. Alternatively, you can contact your local Community Health Worker in Pavee Point at 01-878-0255.

Appendix XI: Research consent form

Maynooth University
National University of Ireland Maynooth

Researcher: Lynsey Kavanagh
Contact number: 01-708-3743

Interview consent form

1. This research, *Exploring Traveller Narratives of Pregnancy Loss: implications for perinatal care* has been explained to me and I understand its purpose.	Yes [ ] No [ ]
2. I have been able to ask questions and all my questions have been answered to my liking.	Yes [ ] No [ ]
3. I understand that this interview is voluntary and I can stop at any time without giving a reason.	Yes [ ] No [ ]
4. I understand that my involvement with the research will not affect my relationship with Pavee Point.	Yes [ ] No [ ]
5. I understand that my name or others mentioned in the interview will not be used in the final report.	Yes [ ] No [ ]
6. I understand that information from this interview will be published but I will not be identified.	Yes [ ] No [ ]
7. I can confirm that I am currently not receiving any follow-up care and/or services associated with my pregnancy loss.	Yes [ ] No [ ]
8. I can confirm that I do not have a current diagnosis of depression and/or other psychiatric illness.	Yes [ ] No [ ]
9. I agree that information given may be used for future publications.	Yes [ ] No [ ]
10. I understand that personal details will be destroyed after this research.	Yes [ ] No [ ]
11. I consent to take part in this interview.	Yes [ ] No [ ]
12. I consent to being audio recorded for the purpose of this interview	Yes [ ] No [ ]

Participant's Name:__________________ **Signature:**__________________

Date:___________________

Researcher: Lynsey Kavanagh **Signature:** __________________

Date: __________________

Further information:
If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@nuim.ie or 01-708-6019. Please be assured that your concerns will be dealt with in a sensitive manner.

Appendix XII: Local authorities' allocation/drawdown on Traveller accommodation 2018

	LOCAL AUTHORITY	ALLOCATION 2018€	Drawdown to date 2018€
1	CARLOW CO. CO.	167,740.00	-
2	CAVAN CO.CO.	30,000.00	-
3	CLARE CO.CO.	853,250.00	13,250.00
4	CORK City Council	310,000.00	-
5	Cork County Council	251,197.00	-
6	DONEGAL CO.CO.	121,800.00	-
7	DUBLIN City Council	1,321,558.39	54,879.69
8	DUN LAOGHAIRE RATHDOWN	673,685.78	-
9	FINGAL CO.CO.	851,189.00	-
10	SOUTH DUBLIN CO.CO.	869,642.50	-
11	GALWAY City Council	176,996.00	-
12	GALWAY CO.CO.	1,080,100.00	36,158.41
13	KERRY CO. CO.	15,350.00	-
14	KILDARE CO. CO.	80,000.00	-
15	KILKENNY CO.CO.	201,682.00	-
16	LAOIS CO. CO.	30,000.00	-
17	LEITRIM CO. CO.	159,614.00	-
18	LIMERICK City& County Council	858,739.00	26,875.00
19	LONGFORD CO CO.	2,922.00	-
20	LOUTH CO.CO.	17,039.00	3,810.00
21	MAYO CO. CO.	30,000.00	-
22	MEATH CO. CO.	65,000.00	-
23	MONAGHAN CO. CO.	400,000.00	29,714.30
24	OFFALY CO.CO.	49,379.00	-
25	ROSCOMMON CO. CO.	230,000.00	102,273.72
26	SLIGO CO. CO.	1,046,095.00	7,656.52
27	TIPPERARY County COUNCILS	25,655.00	38,866.00
28	WATERFORD City & County Council	317,280.00	-
29	WESTMEATH CO. CO.	150,000.00	-
30	WEXFORD CO. CO.	498,801.00	-
31	WICKLOW CO. CO.	209,620.00	19,393.14
	TOTAL	11,094,334.67	332,876.78
	RESERVE	**905,665.33**	

Table 3: Local Authorities Allocation/Drawdown on Traveller Accommodation, Quarter 2, 2018 (Department of Housing, Planning and Local Government, 2018)

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