



Mothers' voices

Exploring experiences of
maternity and health in low
income women and children from
diverse ethnic backgrounds

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Maternity Action is a national charity working to challenge inequality and promote the health and wellbeing of all pregnant women, new mothers and their families.

www.maternityaction.org.uk

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Part 1 – Context

Background

This project was funded by Public Health England (PHE) through the VCSE Health and Wellbeing Alliance (HW Alliance) – a strategic partnership between the Department of Health, NHS England, Public Health England and 21 Voluntary, Community and Social Enterprise (VCSE) organisations selected for their reach into communities experiencing health inequalities. The HW Alliance was created as a result of the 2016 Joint VCSE review, which acknowledged the vital role of the VCSE sector in promoting equality and reducing health inequalities, recommending that NHS commissioners and local authorities work with the sector in order to ‘enable all groups in society, especially those experiencing health inequalities, to have a say in how services can achieve better health and care outcomes’.¹ The HW Alliance is intended to amplify the voice of the VCSE sector and people with lived experience to inform national policy, facilitate integrated working between the voluntary and statutory sectors, and enable co-production of solutions that promote equality and reduce health inequalities, specifically those affecting people with protected characteristics² and Inclusion Health groups.³ Maternity Action is one of the 21 members of the HW Alliance and the UK’s leading charity focusing on protecting the rights and the health and wellbeing of pregnant women, new mothers and their families. This is done through advice work, research, training and national campaigns. Maternity Action’s key priorities include the rights and health of vulnerable migrant women, the impact of working conditions on maternal health and wellbeing, women in prison and immigration detention, access to primary care and breastfeeding rights.

The NHS has many dedicated healthcare professionals and other staff engaged in work to improve health outcomes for low income pregnant women, new mothers and children from diverse ethnic backgrounds, including the most vulnerable. Improving on this work requires an understanding of the areas in which this work is less effective than it could be and of the other barriers to health faced by this group. Black and minority ethnic women and children, especially from low income households, face worse maternal and child health outcomes and are more likely than the rest of the population to be affected by social factors impacting negatively on their mental and physical health and wellbeing. These inequalities and social factors are the focus of this report and its objectives are twofold: Firstly, to increase our understanding of the difficulties faced by black and minority ethnic women on low incomes in terms of managing their health before, during and after pregnancy and when promoting the health of their children. Secondly, to explore the potential of the VCSE sector to contribute to more good work and new strategies underpinning better health for this group.

This report will discuss some VCSE approaches to addressing health inequalities and the social factors underpinning them, as well as some approaches to overcoming barriers to care and support. It will also make recommendations, drawing on PHE’s model of ‘family of community centred approaches’ which includes strands on: strengthening communities, volunteer and peer roles, collaborations and partnerships and access to community resources.⁴ The report is in two parts: a short literature review summarising some of the relevant evidence on black and minority ethnic women’s maternal health, followed by a section discussing the findings from our consultations with mothers and the VCSEs that support them.

The policy context:

Better Births and the Maternity Transformation Programme

This project was carried out in the context of the Maternity Transformation Programme’s improving prevention and population health workstream, which is informed by the findings in the 2016 National Maternity Review, Better Births.

¹ Representatives of the VCSE sector and the Department of Health, NHS England and Public Health England, 2016, Joint review of partnerships and investments in voluntary, community and social enterprise organisations in the health and care sector. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/524243/VCSE_Investment_Review_A.pdf

² According to the Equality Act (2010), these are: age; disability, gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation

³ Inclusion Health Evidence Pack (2010): the unemployed; offenders; care leavers; problematic drug users; people with mental health conditions; the older old (80+); people with physical disabilities; carers; the homeless; people with learning disabilities; refugees; failed asylum seekers; Gypsies, Travellers and Roma; and sex workers

⁴ PHE, 2018, *Health matters: community-centred approaches for health and wellbeing*. Available at: <https://www.gov.uk/government/publications/health-matters-health-and-wellbeing-community-centred-approaches/health-matters-community-centred-approaches-for-health-and-wellbeing#the-family-of-community-centred-approaches>

Better Births set out a vision for maternity services across England to become safer, more personalised, kinder, more professional and family friendly; where every woman has access to information to enable her to make decisions about her care; and where she and her baby can access support that is centred on their individual needs and circumstances. Implementing the vision set out in Better Births through Local Maternity Systems aims to support the Secretary of State's ambition to halve the number of stillbirths, neonatal and maternal deaths and brain injuries by 2030.

The Healthy Child Programme

The [Healthy Child Programme](#) (HCP) is the public health programme (including prevention and early intervention) that lies at the heart of universal services for children and families and is led by Health Visitors. The HCP sets out the evidence based programme for child and family public health and provides both universal and targeted programmes across maternity and infancy (and through childhood-19 years). One of the aims of the programme is 'better short and long terms outcomes for children who are at risk of social exclusion.'⁵

Healthy Start

Healthy Start is a UK-wide statutory scheme to provide a nutritional safety net to pregnant women and children under four in low-income families in receipt of certain benefits or tax credits, and pregnant women under 18. Healthy Start supports public health policies by encouraging breastfeeding and a healthy diet.

Literature review: What we know about the maternal and child health inequalities affecting mothers and children from Black and minority ethnic backgrounds

A literature review was carried out with a view to summarise relevant evidence of health inequalities affecting black and minority ethnic women on low incomes in the UK. On completion of the literature review, a consultation process consisting of focus groups and qualitative interviews took place.

Morbidity, mortality and stillbirth

The risk of maternal mortality among black and minority ethnic mothers in the UK is disproportionately high. According to official figures from 2013-15, the maternal death rate per 100,000 maternities was 6.58 among white women and 28.17 among black women, meaning that black women face a more than four times higher risk.⁶ This disparity also affects smaller ethnic groups in the UK - one landmark study from 2001 found Gypsy and Traveller women to have 'possibly the highest maternal death rate among all ethnic groups' and more recent research from 2017 has noted an increase in health inequalities experienced by Gypsies and Irish Travellers.⁷

Severe maternal morbidity⁸ in the UK follows a similar trajectory with non-white women being around 1.5 times more likely to be affected by serious complications such as acute fatty liver of pregnancy, amniotic fluid embolism, antenatal

⁵ Dr. S. Shribman, K. Billingham, 2009, *Healthy Child Programme – Pregnancy and the first five years*, Department of Health. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/167998/Health_Child_Programme.pdf

⁶ M. Knight *et al.* (Eds.) on behalf of MBRRACE-UK, 2017, *Saving Lives, Improving Mothers' Care: Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2013–15*, Oxford, National Perinatal Epidemiology Unit, University of Oxford, Available at: <https://www.npeu.ox.ac.uk/downloads/files/mbrpace-uk/reports/MBRRACE-UK%20Maternal%20Report%202017%20-%20Web.pdf>

⁷ G. Lewis, J. Drife, 2001, *Why mothers die 1997–1999: the confidential enquiries into maternal deaths in the United Kingdom 41*, London, RCOG Press, and NHS England, 2017, *England Analysis: NHS Outcome Framework Health Inequalities Indicators 2016/17*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2017/07/nhs-outcome-framework-health-inequalities-indicators-2016-17.pdf>

⁸ The WHO Maternal Morbidity Working Group defines maternal morbidity as: "any health condition attributed to and/or aggravated by pregnancy and childbirth that has a negative impact on the woman's wellbeing".

pulmonary embolism, eclampsia and peripartum hysterectomy. The risk remains higher after adjusting for other factors such as age, socioeconomic and smoking status, body mass index, and parity.⁹

Stillbirth and neonatal death are associated with a range of demographic, social and clinical factors. The 2018 MBBRACE report found that the increased risk of neonatal mortality and stillbirth in babies of Asian or Asian British ethnicity had risen from a 38% increased risk to a 66% increased risk between 2014 and 2016. For Black and Black British babies, the risks had remained constant at 121% increased risk for stillbirth and 50% increased risk for neonatal death, compared to babies from a white ethnic group.

Social factors associated with stillbirth include: unemployment and economic deprivation, a history of mental health problems, passive and active smoking, obesity and a history of mental health problems, diabetes and previous stillbirths. Late booking (after 13 weeks) is also associated with an increased risk.¹⁰ A 2007 study comparing Gypsy and Traveller women with a sample of non-traveller UK residents drawn from a range of ethnic and socioeconomic groups, found that, out of 172 Gypsy and Traveller women, 9 of them had experienced a stillbirth. None of the women in the comparative sample had any such experiences.¹¹

Stillbirth, miscarriage and infant death can have mental health implications – one study found an almost four times higher risk of depression and a seven times higher risk of post-traumatic stress disorder in women who had experienced perinatal loss.¹²

Mental health

Black and minority ethnic women as a group experience higher rates of mental health problems and an increased likelihood of experiencing psychosocial risk factors such as poverty.¹³ Despite this, fewer than expected receive diagnosis and treatment for perinatal mental illness.¹⁴ Some of the barriers identified in the literature are: language barriers, stigma and a lack of culturally competent specialist provision for BME women.¹⁵

The link between mental and physical health outcomes is well documented.¹⁶ Untreated mental health problems have impacts on physical health and life expectancy and pre-existing mood disorders are one of the main risk factors for postpartum depression. Other known factors include migration status, exposure to violence and conflict situations and the absence of social support networks.¹⁷ Maternal mental health problems are associated with a range of poor health outcomes in children, including a measurable 'stress response' (raised cortisol levels and higher heart rate) in infants,¹⁸ behavioural issues and mental health problems,¹⁹ and physical health impacts such as asthma, allergies and higher incidences of hospitalisation and emergency care.²⁰ We know that effective social support networks can improve emotional wellbeing and help pregnant women to deal with stress, anxiety and depression.²¹ The case for timely and effective treatment is further strengthened by the evidence that one episode of maternal depression is less harmful for children than chronic or multiple episodes.²²

⁹ M. Knight *et al.*, 2009, Inequalities in maternal health: national cohort study of ethnic variation in severe maternal morbidities, *BMJ* 388: b542. Available at <http://www.bmj.com/content/338/bmj.b542>

¹⁰ J. Gardosi, 2013, Maternal and fetal risk factors for stillbirth: Population based study, *BMJ* 346: f108

¹¹ G. Parry, P. Van Cleemput, J Peters, S. Walters, K. Thomas, C. Coope., 2007, Health status of Gypsies and Travellers in England, *Journal of Epidemiological Community Health*, 61(3): 198-204

¹² K.J. Gold *et al.*, 2016, Depression and Posttraumatic Stress Symptoms after Perinatal Loss in a Population-Based Sample, *J Women's Health*, 25(3): 263-9. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/26258870>

¹³ Public Health England, 2017, Guidance 4. Perinatal mental health, *Better mental health: JSNA toolkit*. Available at: <https://www.gov.uk/government/publications/better-mental-health-jsna-toolkit/4-perinatal-mental-health>

¹⁴ D. Edge, 2011, *Perinatal Mental Health of Black and Minority Ethnic Women: A Review of Current Provision in England, Scotland and Wales*, National Mental Health Development Unit. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215718/dh_124880.pdf

¹⁵ A. Memon *et al.*, 2016, Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England, *BMJ Open* 6(11): e012337, and Imkaan, 2011, *The road to sustainability: A review of Black, Asian, Minority Ethnic and Refugee organisations working with women on health and gender-based violence in England*, available at: https://www.sericc.org.uk/pdfs/2250_the-road-to-sustainability---summary-findings.pdf

¹⁶ Public Health England, 2017, *op. cit.*

¹⁷ *Ibid.*

¹⁸ S. Maggi *et al.*, 2010, The social determinants of early child development: An overview, *Journal of Paediatrics and Child Health*, 46(11): 627-35

¹⁹ K. Turney, 2011, Maternal Depression and Childhood Health Inequalities, *Journal of Health and Social Behavior*, 52(3): 314-332

²⁰ *Ibid.*

²¹ PHE and UCL Institute of Health Equity, 2015, *Local action on health inequalities: Reducing social isolation across the lifecourse*. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/461120/3a_Social_isolation-Full-revised.pdf

²² *Ibid.*

Maternity care

Access to antenatal care is another important factor in maternal health inequalities, as evidence links early booking and continued engagement with services to better maternal, foetal and infant outcomes, and late booking to increased maternal, foetal and infant mortality and morbidity.²³ Black and minority ethnic women tend to access antenatal care later in pregnancy are less likely to access routine screening and to access their post-natal home visits from midwives, compared to non-minority ethnic pregnant women.²⁴ The many barriers to healthcare that migrant women from vulnerable groups face are well documented and arise from a combination of factors that include a lack of resources, demands for documentation and lack of information about how the NHS works.²⁵ In Maternity Action's previous research, women seeking asylum have told us about getting 'blocked' or refused by reception staff acting as gatekeepers, often in conjunction with expectations or experiences of prejudice and discrimination.²⁶ In terms of quality of care, black and minority ethnic women tend to report more negative experiences than white women and are less likely to state that they were treated with kindness by health professionals, or spoken to using terms they could understand.²⁷ They are also less likely to say that they had confidence in the healthcare professionals who treated them and that they were included in decisions about their care.²⁸

The language barriers that affect a large number of BME women can also severely impair the quality of communication between expectant mothers and health professionals, leading to suboptimal care experiences and putting women and their babies in danger.²⁹ The 2007 CEMACH report found that 10% of all maternal deaths between 2003 and 2005 were women who could not speak English.³⁰ Subsequent enquiries have not included this data, meaning that no more current information on the issue exists at present. English-speaking women in groups with lower levels of literacy, including Gypsy and Traveller women, can be similarly affected by impaired communication.³¹ Better Births also highlights the importance of 'providing information in a format which is easy to read and understand, free from complex concepts or medical terminology' when caring for women from different backgrounds and varying levels of English, as well as 'taking extra time to gauge understanding of the language being used'.³²

Socioeconomic and migrant status

UK adults and children from minority ethnic groups are more likely to be living in poverty than their non-minority ethnic peers and unemployment rates are almost twice as high for black and minority ethnic individuals.³³ BME women have been found to be disproportionately affected by austerity and cuts to welfare spending³⁴ and families with children, especially single mothers, have been hit particularly hard by austerity measures since the 2008 financial crisis.³⁵ Black and minority ethnic women are more likely than white women to be single mothers – 59 per cent of black Caribbean, 44 per cent of black African children and 61 per cent of children in mixed race households grow up in single parent families, and nine in ten lone parents are women.³⁶ Research estimates that by 2020, low income black and Asian women will have

²³ R. Haddrill *et al.*, 2014, Understanding delayed access to antenatal care: a qualitative interview study, *BMC Pregnancy and Childbirth*, 14: 207. Available at: <https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-14-207>

²⁴ NPEU, 2010, *Women's outcomes and experiences of care*, Research from the Policy Research Unit – Maternal Health and Care, Oxford University. Available at: <https://www.npeu.ox.ac.uk/prumhc/maternity-care-womens-experience-and-outcomes-218#>

²⁵ Maternity Action, 2012, *Guidance for Commissioning Health Services for Vulnerable Migrant Women*. Available at:

<https://www.maternityaction.org.uk/wp-content/uploads/2013/09/guidancecommissioninghealthservvulnmigrantwomen2012.pdf>

²⁶ Maternity Action, 2014, *Women's Voices on Health*. Available at: <https://www.maternityaction.org.uk/wp-content/uploads/2014/05/Access-to-Primary-Care-report-FINAL.pdf>

²⁷ NPEU, 2010, *op.cit.*

²⁸ *Ibid.*

²⁹ F. Van Rosse *et al.*, 2016, Language barriers and patient safety risks in hospital care: A mixed methods study, *Int J Nurs Stud*, 54: 45-53

³⁰ Maternity Action, 2012, *op.cit.*

³¹ Friends Families and Travellers, 2015, *Inclusion of Gypsy Traveller health needs in Joint Strategic Needs Assessments: A review*. Available at: http://www.gypsy-traveller.org/wp-content/uploads/2015/03/FFT_Inclusion-of-Gypsy-Traveller-health-needs-in-JSNA_FINAL.pdf

³² National Maternity Review, 2016, *Better Births – Improving outcomes of maternity services in England: A Five Year Forward View for maternity care*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf>

³³ Equality and Human Rights Commission, 2015, Factsheet: 'Is Britain Fairer?': Key facts and findings on ethnicity. Available at: <https://www.equalityhumanrights.com/sites/default/files/is-britain-fairer-findings-factsheet-ethnicity.pdf>

³⁴ The Runnymede Trust and Women's Budget Group, 2018, *Intersecting Inequalities: the impact of austerity on BME women in the UK*. Available at: <https://wbg.org.uk/main-feature/intersecting-inequalities-impact-austerity-bme-women-uk/>

³⁵ See, for example, Fawcett Society, 2015, *Where's the Benefit? An Independent Inquiry into Women and Jobseeker's Allowance*. Available at: <https://www.fawcettsociety.org.uk/Handlers/Download.ashx?IDMF=690d472a-38ff-464d-a62f-12488a29ca4a> and

Gingerbread, 2013, *Paying the Price: Single parents in the age of austerity*. Available at: <https://www.gingerbread.org.uk/wp-content/uploads/2017/10/Paying-the-price-in-the-age-of-austerity-full-report.pdf>

³⁶ 59 per cent of black Caribbean, 44 per cent of black African children and 61 per cent of children in mixed race households grow up in single parent families. For more information see the Runnymede Intelligence for a multi-ethnic Britain *Fact Sheet*. Available at: <https://www.runnymedetrust.org/projects-and-publications/parliament/past-participation-and-politics/david-lammy-on-fatherhood/factsheet.html>

lost twice as much money as low income white men due to tax and benefit changes.³⁷ These factors are likely to have significant health implications for pregnant women, mothers and their children. Poverty is closely linked to poor mental and physical health as well as premature death.³⁸ The mother's physical health prior to and during pregnancy are correlated with infant health outcomes including birth weight and gestational age at delivery.³⁹ Recent UK studies have found links between poverty and alcohol misuse,⁴⁰ which is known to cause developmental issues in a foetus that have repercussions on health and well-being into childhood and beyond.⁴¹ Women from low-income backgrounds are also more likely either to be obese or experience slower than average weight gain during pregnancy.⁴² Risks to the foetus from poor nutrition are well known and include low birth weight as well as long term effects such as an increased risk of cardiovascular disease in adulthood.⁴³ In recognition of the effects of poor nutrition, the UK-wide Healthy Start scheme provides low income families on certain qualifying benefits with a 'nutritional safety net' in the form of vouchers for milk, fruit and vegetables as well as free vitamins. This scheme is not available to women who are excluded from the mainstream benefits system by virtue of their migration status. However, pregnant women and mothers of young children who are in receipt of asylum support can apply for extra payments which mirror the Healthy Start payments, although these are paid at a slightly lower rate and do not include free vitamins.⁴⁴

BME women on low incomes are more likely to experience a range of social factors affecting their maternal health negatively. These include poor quality housing (e.g. overcrowded, unsafe, damp and cold) which has been associated with negative impacts on respiratory, cardiac and skin health.⁴⁵ African and African-Caribbean women are also more likely to live in local areas affected by higher levels of air pollution, which is linked to a range of negative child health outcomes including low birth weight, a higher risk of death in the first year of life and poor lung function in later life.⁴⁶

Transient living situations disproportionately affect women from some black and minority ethnic communities and have the potential to disrupt continuity of care, for example the conditions imposed on asylum seekers who are subject to dispersal and suddenly moved away from any existing support networks or care relationships, sometimes more than once during the course of a pregnancy.⁴⁷ Gypsy and Traveller mothers and their families experience similar problems when they are evicted, which happens frequently due to a national shortage of authorised sites.⁴⁸ Both of these scenarios can lead to routine screenings and immunisations being missed.

Recent migrant or asylum seeker status is recognised by NICE as part of 'complex social factors' in pregnancy, warranting extra support and additional attention to continuity of care. Other such factors are difficulties with literacy and maternal age below 20 – factors which are more prevalent in some groups, including the Gypsy and Traveller community.⁴⁹ Dispersal of pregnant asylum seekers and eviction of Gypsy and Traveller women makes it difficult for health professionals to give women optimal maternity care. It also means that any other support, for example from VCSEs or informal peer networks, are disrupted which can leave women at high risk of social isolation. As we have seen, social isolation is associated with an increased risk of perinatal mental health problems. It is also linked with an approximately 30% higher risk of premature death.⁵⁰

³⁷ Women's Budget Group, 2016, News: New research shows that poverty, ethnicity and gender magnify the impact of austerity on BME women, <<https://wbg.org.uk/news/new-research-shows-poverty-ethnicity-gender-magnify-impact-austerity-bme-women/>>

³⁸ See I. Elliot, 2016, *Poverty and mental health: A review to inform the Joseph Rowntree Foundation's Anti-Poverty Strategy*, Mental Health Foundation. Available at: <https://www.mentalhealth.org.uk/sites/default/files/Poverty%20and%20Mental%20Health.pdf> ; Child Poverty Action Group, *The Impact of Poverty*. Available at: <http://cpag.org.uk/content/impact-poverty> ; and M. Violato *et al.*, 2011, Family income and child cognitive and behavioural development in the United Kingdom: does money matter?, *Health Econ.*, 20(10): 1201-25.

³⁹ J. Moss and K. Mullan Harris, 2015, Impact of maternal and paternal preconception health on birth outcomes using prospective couples' data in *Add Health*, *Arch Gynecol Obstet.*, 291(2): 287–298; P. Catalano and K. Shankar, 2017, Obesity and pregnancy: mechanisms of short term and long term adverse consequences for mother and child, *BMJ*, 356: j1

⁴⁰ UK studies suggest that people who experience social and economic disadvantage in early life or adulthood are at greater risk of adopting problem drinking behaviours in later life. L. Jones and H. Sumnall, 2016, *Understanding the relationship between poverty and alcohol misuse*, Liverpool John Moores University Centre for Public Health. Available at: <https://www.scie-socialcareonline.org.uk/understanding-the-relationship-between-poverty-and-alcohol-misuse/r/a11G00000G6QohIAF>

⁴¹ A. Ornoy and Z. Ergaz Z, 2010, Alcohol Abuse in Pregnant Women: Effects on the Fetus and Newborn, *Mode of Action and Maternal Treatment*, *Int J Environ Res Public Health*, 7(2): 364-379

⁴² NICE, 2008, Public Health Guideline: Maternal and Child Nutrition. Available at: <https://www.nice.org.uk/guidance/ph11>

⁴³ J.L. Morrison and T.R.H. Regnault, 2016, Nutrition in Pregnancy: Optimising Maternal Diet and Fetal Adaptations to Altered Nutrient Supply, *Nutrients*, 8(6): 342; T.C. Borge *et al.*, 2017, The importance of maternal diet quality during pregnancy on cognitive and behavioural outcomes in children: a systematic review and meta-analysis, *BMJ Open*, 7(9). Available at:

<http://bmjopen.bmj.com/content/7/9/e016777.info>

⁴⁴ Asylum Support Appeals Project, 2016, *Factsheet 9: Extra asylum support payments for women and children on section 95 and section 4 support*. Available at: <http://www.asaproject.org/uploads/Factsheet-9-Extra-payments-s4-s95.pdf>

⁴⁵ Chartered Institute of Environmental Health, references available at: <http://www.cieh-housing-and-health-resource.co.uk/references/>

⁴⁶ Race and Equality Foundation, 2014, *Air quality and equalities*. Available at:

<http://www.raceequalityfoundation.org.uk/sites/default/files/publications/downloads/air%20quality%20and%20equalities%20-%20final.pdf>

⁴⁷ Maternity Action and Refugee Council, 2013, *When Maternity Doesn't Matter*. Available at:

<https://www.maternityaction.org.uk/2013/11/when-maternity-doesnt-matter/>

⁴⁸ Friends Families and Travellers. More information available at: <https://www.gypsy-traveller.org/policy-publications/>

⁴⁹ NICE, 2010, *Clinical guideline CG110: Pregnancy and complex social factors*. Available at: <https://www.nice.org.uk/guidance/cg110>

⁵⁰ J. Holt-Lunstad *et al.*, 2015, Loneliness and Social Isolation as Risk Factors for Mortality - A Meta-Analytic Review, *Perspectives on Psychological Science*, 10(2): 227-237. Available at: <http://journals.sagepub.com/doi/abs/10.1177/1745691614568352>

Large numbers of black and minority ethnic women in the UK are excluded from the safety net provided by the mainstream benefits system because of their migration status. Some qualify for Asylum Support, which is paid at a rate substantially lower than mainstream benefits.⁵¹ Other migrant women and children are not eligible for either asylum support or mainstream benefits, for example women whose current visa includes a condition of no recourse to public funds (NRPF) and refused asylum seekers whose appeal rights have been exhausted. It is possible to apply for NRPF conditions to be lifted in certain circumstances, for example relating to a child's welfare. If this fails, the last resort is to apply for support from the local authority under Sec 17 of the Children Act. Destitute pregnant women and mothers who have no safety net can end up in precarious living situations and find themselves and their children at risk of exploitation, violence and abuse.

In addition to their exclusion from mainstream benefits, many black and minority ethnic women from migrant backgrounds are also excluded from receiving free NHS maternity care. Maternity care is classed as 'immediately necessary' and cannot be refused for any reason. However, research suggests that NHS maternity care charges (payable at 150% of the regular NHS tariff) constitute an access barrier for many black and minority ethnic women from migrant backgrounds, 'routinely deterring them from seeking timely and regular maternity care', with implications for mental health and wellbeing due to the associated stress.⁵² Maternity care charges are not purely a financial barrier, but also have potential impacts on the ability to regularise migration status - debts over £500 which are outstanding for more than two months are reported to the Home Office and can lead to future visa applications being declined.⁵³ Due to a complex and changing system and the difficulties of proving one's immigration status, many mothers are charged erroneously and others are unsure of whether they will be charged.⁵⁴ Many more women than the chargeable groups are therefore affected.

Lastly, poor working conditions can put women and their pregnancies at risk, particularly in physically demanding jobs with poor health and safety protections. An EHRC enquiry in 2010 focusing on the meat and poultry processing industry heard from low-income women who attributed repeated miscarriages to their working conditions and pregnant women doing unsuitable tasks, such as heavy lifting, under threat of losing their job.⁵⁵ Black and minority ethnic women are also more likely to be in precarious and insecure work situations with few rights and protections and less family friendly provisions including maternity leave and protection from unfair dismissal.⁵⁶ Job loss due to pregnancy and maternity discrimination is a real risk for pregnant women and new mothers, with around 54,000 forced out of their jobs each year as a result of poor treatment at work.⁵⁷ All of these experiences clearly result in high levels of stress and anxiety for pregnant women, which are associated with impacts on maternal and child health outcomes, such as shortened gestational age.⁵⁸

The role of the VCSE

There is a wealth of data showing that mothers from black and minority ethnic backgrounds experience worse maternal and child health outcomes, as well as being more likely than non-minority ethnic mothers to experience the social factors that contribute to health inequalities, such as inadequate housing, poverty and language barriers. Often, these issues are addressed through VCSE interventions, such as advice work and peer-support. The public health contribution of VCSE organisations is widely acknowledged, for example in the NHS Five Year Forward View, which calls for stronger partnerships with charities and community organisations, noting that they, 'deliver vital services with paid expert staff', are often 'better able to reach underserved groups, and are a source of advice for commissioners on particular needs'.⁵⁹ Despite often being very well-regarded, the lack of financial capacity for grassroots organisations to carry out evaluations and publish literature on their work means that they very often experience difficulties getting commissioned. The policy background for the new models of care which includes Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) emphasises the importance of engaging with local communities. However, a recent review by the House of Commons Health and Social Care Committee indicates that such engagement between STPs and

⁵¹ Current asylum support rates available at: <https://www.gov.uk/asylum-support/what-youll-get>

⁵² Maternity Action, 2017, *The impact on health inequalities of charging migrant women for NHS maternity care: A scoping study*. Available at: <https://www.maternityaction.org.uk/wp-content/uploads/ChargingReportMarch2017FINALcompressed.pdf>

⁵³ Maternity Action, Information sheet: Dealing with debts owed to the NHS for maternity care <<https://www.maternityaction.org.uk/a-guide-to-dealing-with-debts-owed-to-the-nhs-for-maternity-care/>>

⁵⁴ Maternity Action, 2017, *op. cit.*

⁵⁵ EHRC, 2010, *Inquiry into recruitment and employment in the meat and poultry processing sector report*. Available at <https://www.equalityhumanrights.com/en/publication-download/inquiry-recruitment-and-employment-meat-and-poultry-processing-processing>

⁵⁶ TUC, 2017, *Insecure work and Ethnicity*. Available at: https://www.tuc.org.uk/sites/default/files/Insecure%20work%20and%20ethnicity_0.pdf

⁵⁷ EHRC, 2018, *Pregnancy and maternity discrimination research findings*. Available at: <https://www.equalityhumanrights.com/en/managing-pregnancy-and-maternity-workplace/pregnancy-and-maternity-discrimination-research-findings>

⁵⁸ V. Glover, 2014, Maternal depression, anxiety and stress during pregnancy and child outcome; what needs to be done, *Best Pract Res Clin Obstet Gynaecol*, 28(1): 25-35; P.J. Brunton, 2013, Effects of maternal exposure to social stress during pregnancy: consequences for mother and offspring, *Reproduction*, 146(5): R175-89

⁵⁹ *The NHS Five Year Forward View*, available at: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

the VCSE sector is still 'very limited' and highlighted that funding cuts have made it hard for smaller charities to engage with STPs.⁶⁰

Summary

In summary, we know that BME women on low incomes experience higher risk of poor perinatal health and worse maternal and child health outcomes. Poverty is a key factor. Other factors are the access barriers to maternity care that black and minority ethnic women encounter and their disproportionate exposure to a range of risk factors associated with negative impacts on physical and mental health and wellbeing for both mother and child.

The study

Aims, methodology and analysis

The aims of this study were twofold:

1. To increase our understanding of the difficulties faced by black and minority ethnic women on low incomes in terms of managing their health before, during and after pregnancy and when promoting the health of their children.
2. To explore the potential of the VCSE sector to contribute to more good work and new strategies underpinning better health for this group, by addressing some of the factors identified.

A series of ten focus groups were held in order to gather data about women's experiences. Eighty-one participants were recruited through our extensive networks of community organisations, who were able to put us in touch with women from black or minority ethnic backgrounds with lived experience of pregnancy and maternity in the last five years or so. A small number of women without children attended on the basis of planning a pregnancy but the number of women in the 'preconception' group is likely to have been greater, given that at least some participants would be likely to have more children in the future.

Focus groups were held across a number of locations with relatively high levels of economic deprivation: Central Birmingham, Central Manchester and the two London Boroughs of Hackney and Southwark. In light of discussions with PHE and out partners in the HW Alliance, focus groups with a number of underserved community groups experiencing particularly poor health outcomes were also held outside of these locations. The community groups were: asylum seekers and refused asylum seekers, Gypsy and Traveller women, Polish- and Romanian-speaking Roma women, Orthodox Jewish women and Spanish-speaking Latin American women.

Each focus group session began with a short introduction to the project and its focus on health during pregnancy, maternal health and child health during the early years. Consent and confidentiality information was read out to the group and consent forms distributed.⁶¹ Discussions were then allowed to develop organically around three open-ended questions. Focus group participants were asked what 'good health' meant to them, whether they found it easy or difficult to have good health and what the factors were that influenced their health positively or negatively.⁶² The discussion was then framed around the topics raised by participants, meaning that some different topics were discussed in different groups, although there was also a great deal of overlap. A list of topics drawn from the literature review was used to prompt discussion where needed. This list was expanded to include a number of pre-pregnancy topics for the final two focus groups, upon request from PHE. Not every topic on the list was covered in each focus group.

For our second objective, examples of local practice were gathered from twenty VCSE organisations supporting black and minority ethnic women on low incomes with issues affecting their health and wellbeing. This was done through a series of short interviews asking organisations about their work and about the main issues facing their service users.⁶³ VCSEs that were selected for interview included national organisations and local VCSEs in the four geographical locations, as well as specific organisations supporting the women in the aforementioned seldom heard communities. We also reached out to organisations for women with specific support needs, such as migrants with NRPf conditions, breastfeeding mothers, working mothers, women seeking asylum and socially isolated mothers. Due to the limited resources that usually characterises VCSEs working at community level, these 'local practice examples' (which are highlighted throughout the report) were chosen on the basis of qualitative evidence including service user feedback and a history of well-regarded work, rather than substantial evaluation processes or return on investment analyses.

⁶⁰ House of Commons Health and Social Care Committee, *Integrated care: organisations, partnerships and systems*, Seventh Report of Session 2017–19. Available at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/650/650.pdf>

⁶¹ Appendix 1 and 1a. (In the group for Polish and Romanian speaking women, the form was verbally translated.)

⁶² Appendix 3: Focus group discussion items

⁶³ Appendix 5: VCSE interview questions

Focus groups and interviews were recorded, transcribed and subjected to thematic analysis. The most strongly emerging themes from the consultations are reported in the 'findings' section.⁶⁴

Limitations:

- The focus group format may not be optimal for discussion of stigmatised issues like domestic violence, mental health or substance misuse. It is worth noting that children's centres, where some focus groups were held, are statutory facilities with connections to Health Visiting services. This may have placed some limitations on the discussion.
- We know that domestic violence affects as many as one in every four women and many VCSEs interviewed as part of the consultation mentioned it as one of the main challenges for their service users. Yet violence from a partner was mainly discussed in general terms in focus groups, as opposed to personal experiences.
- Due to childcare considerations, it was necessary for most focus groups to take place in the presence of young children. This may have had some impact on the discussion.
- Focus group participants were recruited through VCSEs supporting them with difficulties relating to their health or social situation - a deliberate choice, given the consultation topic. This meant that focus group participants would have been more likely to mention negative experiences than may otherwise have been the case.
- Examples of local practice are based on qualitative evidence such as service user experiences rather than impact assessments or return on investment analyses. Small grassroots VCSEs generally lack the capacity for substantial evaluation programmes and this was also the case with the organisations that we interviewed for our consultations.

⁶⁴ Some quotes are verbatim. Others have been shortened and/or edited for clarity.

Part 2 – Findings

Access and Effective Use of Health Services:

Negative experiences of healthcare

- Negative experiences of healthcare were associated with prejudice and discrimination and not having legitimate concerns taken seriously.
- Experiences of prejudice and discrimination were often associated language and communication barriers and insufficient cultural competence on the part of health professionals.
- Barriers to care included being refused GP registration because of migration status or ethnicity and not being able to access interpretation services.
- VCSE approaches to these problems included: linking specially trained health professionals with local ethnic communities, legal advice services and holistic approaches combining direct support and bridging with other services, sometimes in a community language.

Respect - *'They don't care for us too much'*

We know that women from BME backgrounds are more likely than white women to report negative experiences of care and experience severe maternal morbidity, birth complications and stillbirth. As we have seen, they are also more likely to report poor treatment from health professionals and that they were not listened to. A number of women in our focus groups had experienced traumatic events in hospital. In these women's view, some of the factors surrounding these traumatic events related to being part of an ethnic minority and to the failure of health professionals to take their concerns seriously.

One focus group participant, who had been told that she had a high-risk pregnancy, for which she had been getting extra attention from the community midwife, told us that when she entered the hospital, there was no additional monitoring. During the birth, she experienced severe complications which resulted in an emergency hysterectomy, which was described as 'having destroyed her life'. She believed that the hospital had acted neglectfully and attributed their neglect to the fact that her local hospital catered mostly to the local Asian community and was under-resourced for this reason.

"Because the hospital, it caters to Asian communities and we feel that they don't care for us too much. They don't. My experience was very bad. [...] they removed my womb, they destroyed my life – I think they have! They told me, 'We have investigated everything, there is no negligence from our side'. But I am always thinking, there is something, just need to look properly."
(Focus group participant, Children's Centre, Birmingham)

Stillbirth – *'They didn't listen'*

1 in every 225 births ended in stillbirth in 2016. Although miscarriage affects 1 in 4 women, it happens during the first trimester in about 75% of cases.⁶⁵ Black and minority ethnic women are at increased risk of stillbirth. Four women across two focus groups told us about experiencing stillbirth or late miscarriage either one or more times in their lives. Some of these incidences had taken place over twenty years ago, others were recent. Several women in the Gypsy and Traveller focus group told us about mothers and other relatives who had been through stillbirths more than once. The total number of women who were affected is likely to have been higher than four as the subject only came up in the two aforementioned groups and was not one of the main discussion items on the list of prompts.

In at least two cases, focus group participants attributed the stillbirth to the failure of hospital staff to listen to the concerns of labouring women and their families. Other factors included the disruption to the continuity of care, where women had moved and attended several different health services during their pregnancy. (Continuity of care is discussed in more detail in the next section.)

"They knew she had a narrow pelvis. She was only not even 17 at the time. And then when she went into hospital, she presented her file that she moved up and down with for the past nine months, but they didn't take no heed of her small pelvis. They said, 'Oh, that's nothing. We can get the baby through.' She was in labour for 4

⁶⁵ Statistics about early miscarriage, late miscarriage and ectopic pregnancy available at the Tommy's website: <https://www.tommys.org/our-organisation/charity-research/pregnancy-statistics/miscarriage>

days and the baby was distressed and ended up being a stillbirth. And every one after that she had to have a C-section.”

It was the hospital's fault.

[Facilitator:] So, she had been moved, throughout her pregnancy she had been going to different places, is that right?

Yeah, but carried her file with her, so when she presented it, they should have looked and said, 'She's been recommended for C-section because her pelvis is too small.' Actually, my dad raised the question at the time and my nan came and they went to the doctor and they said, 'Look they've said she can't have the baby like this.' And he said, 'No, no, that's just someone's opinion.'”

(Focus group participants, FFT, Brighton)

“I was having twins. And I lost one at 14 weeks. The other twin was doing fine. And then when I went into labour I was 48 hours in labour and I haemorrhaged, when your waters go I haemorrhaged. They should have brought me in for an emergency operation. They told my mother-in-law and my mother to let me go in and get a shower. My mother said, 'That's not right for her to have a shower, should you not bring her in for a section?' I was 19. They said, 'No, no, no, no.' And when they put the thing on me, the heart monitor, it showed the baby was in distress. I was 48 hours in labour and the baby died when she was born. So, it was down to them, because the whole time she was in distress. They didn't listen to my mother. 'Look,' she said, 'I've buried 3 children like this. I don't want this to happen to her.' It did.”

(Focus group participant, FFT, Brighton)

Experiences of prejudice – ‘We’re mothers, the same as any other mother’

The literature shows that, in addition to having worse maternal and child health outcomes, black and minority ethnic women are also more likely to experience barriers to care, including experiences and expectations of prejudice and discrimination. We have also seen that engagement with maternity services is particularly important for this group of women. However, the expectation of poor treatment, sometimes based on past experiences, can be a powerful deterrent.

Mothers in the focus groups that were hosted by VCSEs supporting women seeking asylum, Gypsy and Traveller women and Roma women frequently told us that they had experienced varying degrees of prejudice and discrimination when accessing midwives or other health services – sometimes being denied access. These experiences were often associated with issues around language and communication and a lack of cultural competence among health professionals and support staff. These findings reflect the sentiments expressed in the National Maternity Review on the subject of caring for women with different backgrounds, which noted the importance of understanding lifestyle choices and cultural differences, as well accessible communication.⁶⁶

“Most times, when they see that you cannot speak like them, they won't attend to you.”

(Focus group participant, WAST, Manchester)

“I don't even get to see the GP, it's the reception. She not friendly at all, and when she knows that we are not from here, that we can't speak 'properly', she intimidates you.”

(Focus group participant, WAST, Manchester)

“If you have your first child you don't know to speak and you have difficulties communicating, you risk your child's life in this. Health professionals don't want to help and then even though they do have interpreting available, they do have means of helping, they just refuse to do that. In some ways it is even racist behaviour from the health professionals.”

(Focus group participant, through translator, Roma Support Group, London)

“One day, my blood pressure was up high. I couldn't get to the midwife because I was told to stay in bed by the doctor. And then she wouldn't come because I was on site. Would she have done that with someone who lived in a house? No. See, that's how you come down to fall down the ladder. It's that easy. But that's why we've got to let them know that we're mothers the same as any other mother, and entitled to rear your child in your lifestyle, as long as it gets reared in the right way, in the right conditions. You've got that right.”

(Focus group participant, FFT, Brighton)

One VCSE organisation we interviewed, which supports women seeking asylum, talked about the negative mental health impacts of constantly encountering people with negative preconceptions about black and minority ethnic people, migrants and asylum seekers. Another VCSE supporting Gypsies and Travellers told us that service users had been denied GP

⁶⁶ National Maternity Review, 2016, *op. cit.*

registration on the basis of their ethnicity and identified racism and prejudice as the main barrier to care for their service users.

“Some of it is direct racism, where they’re living, because they are in very white areas. And then they get stigmatised and victimised in the way they do nationally and the people respond to what’s in the papers. So, they are dealing permanently with negative images and negative general stigma in terms of their mental health. They have this ‘Asylum Seeker’ label stamped on their head, that they can’t get away from, that dismisses anything else that might be going on in their lives. I think that’s a very important issue in terms of their mental health, but also in terms of how services see them.”
(VCSE community worker, WAST, Manchester)

“A colleague had taken some Travellers to register with the GP. When they asked what their names were, it was a common Irish Traveller name and they said, ‘Oh no we are not having any more [Name] here.’ If she just changed that to ‘Mustapha’ or ‘Patel’, can you imagine? But that GP surgery felt it was ok to say that. It is often described as the last bastion of tolerated racism.”
(VCSE community worker, FFT, Brighton)

Migration status should not be a barrier to accessing GP services, as registration cannot be refused on the basis of homelessness, lack of documentation or immigration status.⁶⁷ However, we know that migrants often struggle to access primary care for various reasons relating to their status and the situations in which they find themselves as a result of their status.⁶⁸ The mother of a newborn baby told us that she had been refused healthcare and unable to access a midwife until 21 weeks, causing her to miss out on routine screening. She had been turned away from the GP service on the basis of her migration status. She had spent her pregnancy being both physically unwell and experiencing anxiety about the baby’s health, until she received VCSE support that enabled her to register with a midwife, something which she had been entitled to all along.

“I was told nobody could see me because I didn’t have residency. I don’t know how this works, to have a GP. Until I met Doctors of the World, I didn’t know what my rights were. And that I could actually go in and register, whether I was a resident or not. So, my pregnancy [progressed] for months.
[Facilitator:] Do you know when you saw the midwife, when you had your first appointment?
I was 21 weeks.
[Facilitator:] Do you think it affected your health in any way to book that late?
Yeah. I was not fine. And I couldn’t even take anything. I took paracetamol, but it wasn’t working, so I just stopped and I had to be in pain. I just didn’t know what to do, and I didn’t want to self-medicate. I had my first scan at 23 weeks. So, I missed all the... something for Down’s syndrome. I just had the anomaly scan. I wanted to know what is going on with me and the baby. Most of the time, I ended up crying. But now I have a midwife. It’s good.”
(Focus group participant, Hackney Playbus, Hackney)

Breaking down barriers

VCSEs told us about providing holistic services to a particular community, addressing a wide range of barriers to maternity care, for example relating to language, migration issues, discrimination and maternity care charges.

“We provide women with Spanish language support to access their rights – anything from accessing benefits to healthcare, education, employment rights, making sure that they are not getting exploited or supporting them if they are in that situation. We also have a legal advice service and domestic violence support, sexual violence support, including trafficking and prostitution. Support is provided via drop in sessions, and telephone advice services as well as appointments with caseworkers. There is also an immigration lawyer and a family services lawyer available to book appointments with.”
(VCSE Community worker, LAWRS, London)

“We have a 24 hour helpline and take 10-15 calls a day about problems in early pregnancy including physical, emotional problems, complications, postnatal problems, breastfeeding, bleeding – anything! Even financial problems, wanting to stay longer in hospital, having had a bad experience in hospital. The women trust me so I can advocate for them, or I know where to signpost them to.”
(VCSE Community Worker, JuMP, London)

⁶⁷ NHS England, *How to register with a doctor (GP)*: <<https://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Documents/how-to-register-with-a-gp-homeless.pdf>>

⁶⁸ Maternity Action, 2014, *op. cit.*

VCSE community workers emphasised the importance of creating familiarity and trust between sometimes socially isolated communities and time-poor healthcare professionals who may not have the resources to initiate such efforts alone, helping to build positive relationships in the absence of which women could be missing out on essential care during their pregnancies. One example that appeared to have had some success was the practice of linking a specially trained health professional with a local ethnic community.

[Facilitator:] The health visitors, do they come out to site?

Yeah, they do now, they never used to

[VCSE community worker:] 20 years ago, we asked the local health visiting service how many contacts had they had with the Traveller sites in the last six months? And they said, 'Oh no, it's fine. We like the Travellers, so it's fine, they can come to us.' We asked them how many women they'd seen in the last six months and they said, 'Four.' And so, in the same period of time, six months, by just going out onto site with another Traveller, [the specialist health visitor working with FFT] saw 127 people, compared to four. That's a big gap."

(VCSE community worker and focus group participants, FFT, Brighton)

"There used to be a midwife that would go to the Travellers' sites. This was a few years ago, then people would come back because they trusted her, she got a reputation. She got to know the Travellers, and the Travellers got to know her."

(VCSE community worker, FFT, Surrey and Sussex)

Continuity of care

- Women who had moved from the initial place of booking told us about the disruption to continuity of care and VCSE support. Some had been refused access to maternity care in a new area.
- Additional challenges included expectations of poor treatment as well as issues around literacy, communication and confidence.

NICE recognises asylum seekers and women who have difficulty speaking or reading English, as well as pregnant women under 20, as experiencing 'complex social factors' in pregnancy. Additional measures on behalf of healthcare professionals as well as local commissioners are therefore recommended, such as extra attention paid to continuity of care in recognition of the additional risks involved.⁶⁹ These factors are particularly relevant to women from black and minority ethnic communities. For example, many women in the Gypsy and Traveller community are under 20 when they have their first child and literacy levels, as in many other BME communities, are low compared to the general population.⁷⁰ Literacy issues put women at a disadvantage in terms of informed choice and self-advocacy.

Dispersal – 'it disorganises everything'

Several women in the focus group for asylum seekers told us about being moved to different areas one or more times during their pregnancy or in early motherhood – a practice known as dispersal. The women told us about having to 'start all over again', in terms of making contact with maternity services and going over their medical history, which may have included issues requiring special attention during pregnancy, such as PTSD, gender-based violence and abuse such as FGM, all of which are associated with stigma – a strong barrier to disclosure. This appeared to be a daunting prospect – especially coupled with the expectation of poor treatment which is often present in this group.

[Facilitator:] What happens to your maternity care when you get moved?

You have to abandon it and start again. So, when I move, they don't know if you will go back. My blood pressure is very high now, so they are trying to monitor it now, at the GP. Because of the stress. It's not really nice, starting again, all over again. Not like someone who already knows your story. You have to start explaining again. And the person you will meet – the person is not even going to be nice! They will treat you bad."

(Focus group participant, WAST, Manchester)

As well as increasing the risk of maternal and child morbidity and mortality associated with disruption of care, dispersal also severs any existing supportive relationships with local VCSEs or a trusted midwife – factors that can also have wider positive impacts in terms of emotional wellbeing. One VCSE told us about building relationships with pregnant women

⁶⁹ NICE Clinical guideline CG110: Pregnancy and complex social factors (2010) recognises complex social factors as: alcohol or drug misuse, recent migrant or asylum seeker status, difficulty reading or speaking English, aged under 20 and domestic abuse. Guidance available at: <https://www.nice.org.uk/guidance/cg110>

⁷⁰ Friends, Families and Travellers, *Working with Gypsies & Travellers... A brief note for Health Practitioners*. Available at: https://www.gypsy-traveller.org/pdfs/working_health_gypsies_travellers_guide.pdf

experiencing multiple needs, including poverty and mental health problems, only for the support to suddenly stop when women are dispersed.

“There are so many complex issues [apart from mental health], obviously money, finance is another major issue, that we have to deal with, and it’s very much about some women having no recourse to public funds, so it’s referring them to food banks... And then they get dispersed to different parts of the country and we never see them again.”

(VCSE Community Worker, Bethel Doula, Birmingham)

‘We are Travellers - we constantly get moved’

Travellers are frequently evicted from where they live, due to a national shortage of authorised sites. Women from this community talked about being ‘moved on’ by police whilst pregnant or ‘with a screaming infant in their arms’. Apart from being stressful, being evicted can also cause continuity of care problems – women told us about being refused access to midwives in a new area because initial booking had taken place elsewhere, sometimes having to travel over 150 miles to attend appointments and give birth. It is not difficult to see how this could lead to disengagement with services, especially towards the end of a pregnancy when check-ups are more frequent.

“I had to go back to have the baby where I originally lived. But we are Travellers, we travel up and down, we constantly get moved. Throughout the pregnancy, constantly being moved on. But then I had to go back, for two weeks, to have the baby. So, when you went to a new area, they wouldn’t allow you to see a GP or a midwife, they said you had to go back. So, I used to drive 170/180 miles one way, and back again to see a midwife.”

(Focus group participants, FFT, Brighton)

The problem is further exacerbated when women are unable to read their hand-held notes, as more emphasis is placed on the pregnant woman to voice any concerns based on what she knows about her pregnancy and her health. Focus group participants told us that the stigma associated with a lack of literacy made them embarrassed to admit they needed help in this area which gave rise to communication barriers. (Communication barriers are discussed further on in the report.)

Language and communication

Language barriers – ‘When they see that you don’t speak English, they just ignore you’

- Availability and quality of interpreting services was one of the most frequently mentioned barriers to maternity care. The problems were articulated both in terms of communication barriers and in terms of being deterred from engaging with services.
- Some women were concerned that their limited English signalled vulnerability in terms of exercising rights and entitlements.
- Language barriers have negative impact on women’s ability to make informed and active choices about their maternity care.
- VCSE approaches to language barriers included: one-to-one peer support in community languages and advocacy.

As well as additional time and flexibility, NICE also recommends the use of ‘a variety of means to communicate’ with pregnant women who have difficulty reading or speaking English, as they may otherwise fail to ‘make full use of antenatal services’.⁷¹ As has been discussed previously, there is good evidence in favour of encouraging women to engage with services, as this is associated with better maternal and child health outcomes. Black and minority ethnic women are more likely than white women to experience a language barrier.

Language and communication barriers were frequently identified as big problems by both focus group participants and VCSEs, both with regards to accessing and making effective use of services. More than half of the VCSE organisations we interviewed named language as one of the main issues affecting the pregnant women and new mothers they support.

According to Bright Beginnings – a VCSE providing one-on-one peer-support in a number of community languages to vulnerable pregnant women, service users often find that their need for an interpreter has been disregarded, even when recorded in their notes, frequently causing stress and anxiety as the pregnant woman undergoes tests and other procedures that are not explained to her, or not explained in a way that she can understand. This is at odds with the current vision for maternity services set out in the National Maternity Review, in which ‘every woman has access to

⁷¹ NICE, 2010, *op. cit.*

information to enable her to make decisions about her care; and where she and her baby can access support that is centred on their individual needs and circumstances'.⁷²

Bright Beginnings also highlighted how prejudiced and discriminatory treatment of women who spoke little or no English effectively discouraged them from attending their appointments. This was echoed by many focus group participants and other VCSEs, not only with reference to maternity services but also when attending GP practices and hospitals. This illustrates the need for advocacy support for women who may otherwise have great difficulty accessing the care they need and are entitled to.

*"In a lot of the cases we have, the women get treated really badly and they get discouraged to use the services. If you are made to feel bad every time you show up for an appointment, you may be reluctant to go."
(VCSE Community worker, Bright Beginnings, London)*

*"When they see that you don't speak English, you don't know your rights, you don't know how to communicate, they just ignore you. Language is a big, massive barrier."
(Focus group participant, through translator, Roma Support Group, London)*

Polish- and Romanian-speaking women in our Roma focus group, the vast majority of whom spoke very little or no English, said they were usually denied interpreting services by health professionals, who were perceived as generally unhelpful. One woman said the only time she had been provided with a phone interpreter through Language Line was after she got 'really angry and started shouting at the practice staff' when her daughter was very unwell. She said: 'I couldn't take it anymore – I just exploded.'

*"There's a problem with understanding everything the doctors says. Asking friends or family members who speak English is not the perfect situation. If the doctor is nice, or understanding, he or she might go online for some translation. And they try and communicate this way. But not always. In order to get an interpreter, you need to book in advance a week or two. If it's an emergency appointment there is no chance to get anyone."
Translator summarising focus group discussion, Roma Support Group, London)*

Many Spanish-speaking women revealed similar problems, although they were slightly more likely to have had language support of some kind and their experiences with health professionals were generally described in more positive terms.

*"I don't speak perfect English. So, I can't find out about, or I can't ask the specific questions that I would have liked to have asked... But they did look after me well. The only problem was the language in my case."
(Focus group participant, Espacio Mama, Southwark)*

A lack of consistency across different hospitals and between primary and secondary care settings was flagged up both with regards to availability and quality of interpreting services. Focus group participants told us that sometimes interpreters did not do the job properly and some women had paid out of their own pocket for someone to translate for them.

*"I had a bad experience with the translators. I understand English, I speak a bit of English, but at that time I was in the middle of a really difficult breakdown and I couldn't understand, I asked for a translator. The translator translated for me but she was saying the complete opposite to what the doctor was saying! That translator wasn't what she ought to have been. That happens quite a lot."
(Focus group participant, Espacio Mama, Southwark)*

Communication – 'Who understands a doctor?'

- Use of medical jargon was highlighted as a communication barrier, causing anxiety when undergoing tests and screenings without knowing their purpose.
- Women with limited literacy were unwilling to ask for clarification due to concerns about stigma and negative judgement from healthcare professionals.

Issues with literacy and accessible communication can have similar impacts to language barriers. Women told us about low levels of literacy and the difficulties this caused when communicating with health professionals. Focus group participants felt that it was stigmatising and embarrassing to admit if they could not read and write, which made it more difficult to ask for clarification when they needed it.

"Well, quite a lot of people in the Travelling community can't read, they can't. They don't know how to approach a person and they don't know what to ask them for... Because they've got one way of speaking and you've got another way of speaking. People talk big words what they don't understand."

⁷² National Maternity Review, 2016, *op. cit.*

It makes you feel worried because you think to yourself, well I don't know what she's saying. And then you're worried and thinking, is this woman watching everything I'm doing? And you don't want to embarrass yourself."
(Focus group participants, FFT, Brighton)

Women in this group also talked about the impact of communication barriers when undergoing various antenatal tests and screening processes, leaving them wondering whether something was wrong with the baby but not wanting to ask.

"You go in and you have your first antenatal and you've got all these bloods coming out of you, and no one bothers to say to you, 'Well this was for this, this is what we're going to test you for and we need to know this because of this.' They just come through, and then you're sitting there wondering, well what's that for."
(Focus group participant, FFT, Brighton)

NHS maternity care charges – 'It adds a lot of stress'

- There was a high level of confusion surrounding NHS maternity care charges. One woman appeared to have been charged in error and several others were unsure about their chargeability.
- VCSEs told us about the mental health impacts of charging and how it could discourage women from engaging with maternity services.
- VCSE approaches included: specialist legal advice and information, casework and advocacy as well as emotional support and encouragement to attend appointments.

We know from previous research that NHS charges constitute a barrier to maternity care which mainly affects migrant women from black and minority ethnic communities. This happens in a number of different ways:⁷³

- Women who are chargeable, and women who do not know whether they are chargeable, are deterred from engaging with maternity services because they cannot pay the charges;
- Women who are chargeable, and women who do not know whether they are chargeable, are deterred from engaging with maternity services in case they are reported to the Home Office for outstanding debts, which can impact negatively on future visa applications;
- Women who are not chargeable are pursued for charges due to the difficulties of proving migration status and deterred from using services they are entitled to access for free.

Some level of confusion prevails among both pregnant women and hospitals' overseas visiting managers (OVMs) about the rules and regulations surrounding NHS maternity care charges⁷⁴ and this was also reflected in the focus groups. Several participants asked us whether they needed to have worked for a specific period of time in order to be eligible for free NHS maternity care. One woman had been billed over £14,000, despite having paid the Immigration Health Surcharge (IHS). Although evidence of the IHS payment had been sent to the hospital, along with a printed information sheet from Maternity Action, the hospital had failed to cancel the last £4000. Understandably, this was causing her a lot of stress and she was referred to Maternity Action's Maternity Care Access Advice Service (MCAAS), which provides specialist legal advice. Previous research has highlighted the importance of expert advice and advocacy from VCSEs, as vulnerable women are unable to afford the kind of legal advice they need to challenge charges, which are sometimes made in error due to a lack of knowledge about immigration legislation on the part of OVMs.⁷⁵ This was echoed by VCSEs.

"Is it true that when you give birth, you have to pay for the care? Recently, when they did the check-up, they made me present my I.D. and my National Insurance Number so they could check whether I'm working. Could you get a letter saying you have to pay? Because I've heard of cases.

I got one!

I got a letter saying that I had to pay, I don't know how much, if I didn't have the right documents, some sort of rate that they pay and I don't know what else, that I have to have worked, something like that. So, I sent them those documents in writing with a letter.

After the pregnancy I lost, I got that letter that said the amount and [asked] if I had documents."

(Focus group participants, Espacio Mama, Southwark)

"They sent me a bill, two bills actually. One for £4000 and one for £10,000, I said, for what? They said, 'Sorry, sorry, sorry, it's just the first one, for £4,000, forget about the £10,000'. I said, 'I will just forget about the whole thing. Because where am I going to get the £4,000 to pay? I've paid the IHS [Immigration Health Surcharge]! The Maternity Action article is there, I've sent it to you. What do you want me to do? Why are you still badgering me?"

⁷³ Maternity Action, 2017, *op. cit.*

⁷⁴ *Ibid.*

⁷⁵ *Ibid.*

Why is it still on my name? I don't understand!"
(Focus group participant, Children's Centre, Hackney)

VCSEs supporting women who were being charged, or concerned about being charged, told us that they were seeing mentally stressed service users who were also being discouraged from engaging with maternity services and other support services, out of fear or being sent bills they could not pay, or being reported to the Home Office. The mistrust of services could also affect VCSEs ability to support women – one VCSE community worker said that a service user had recently asked whether her details were going to be passed onto the Home Office.

In addition to providing advice and support with the charging process, VCSEs also told us that they actively encourage women to attend their maternity care appointments in order to minimise the health risks associated with late booking and low attendance.

"We see a lot of people with maternity bills. Again, people with NRPF that don't have enough money to pay for basic things, don't have money to pay £5,000. And it adds a lot of stress, and the fact it may affect their immigration application. Women who have been charged have health issues, they are on very, very low incomes or no incomes, and that puts a strain on people's mental health. That's something that I can detect when I'm dealing with a woman – she'll tell me how stressed she is."
(VCSE Community Worker, MCAAS Maternity Action, National)

"Women who have mental health conditions, or emotional wellbeing support are worried about accessing other services, because they are worried about how their information will be shared. I've recently been asked 'Will you tell the Home Office about me?'"
(VCSE Community Worker, Bump Buddies, London)

"I think we get to really see the impact of charging for maternity care at [local hospital]. Women are choosing not to have maternity care. Our message in the program is very clear, we encourage women to get maternity care regardless of if they will be billed. We think it's better that they have maternity care and get the bill than try and not get maternity care and something goes wrong, medically."
(VCSE Community Worker, Bump Buddies, London)

One focus group participant, who was also a volunteer doula (though not with the VCSE we were visiting), told us about a woman who had insisted on giving birth without any involvement from health professionals, out of fear of being charged, deported or having her child taken away. Luckily, there had been no complications in this particular case.

"This lady had no antenatal care, no nothing. She had the baby at home. It was fine, baby is lovely. She didn't have nothing, because they didn't have money. They couldn't pay, and they were frightened to go to the NHS in case they either took the baby off them or sent them back."
(Focus group participant/community doula, FFT, Brighton)

Apart from legal advice and casework support to women who were unsure about charging, who had been charged in error, or needed to negotiate a payment plan with the hospital, peer-mentoring was also identified as a useful approach to informing women about their rights and encouraging them to engage with maternity services.

"There is a massive amount of casework that we don't have capacity to take on so what I do is, I advise in such a way that a woman can lift my advice out of the email and use it to write a letter to the hospital. Or, if I've got capacity I can take it on and contact the hospital on her behalf."
(VCSE Community worker, Maternity Action MCAAS, National)

"It is a lot about awareness raising, how the system works, that you have the right to register with a GP, what is involved with Maternity Care, because a lot of women don't know or they are scared to be charged. We really stress the importance of going early for your maternity care."
(VCSE Community Worker, Bright Beginnings, London)

The impact of expectations – 'In my country, we don't have midwives'

- *Late booking was sometimes associated with low expectations of care. Several women told us there was no maternity care at all in their country of origin*
- *Conversely, the expectation to see a doctor meant that some women viewed appointments with midwives as constituting a lower standard of care, which sometimes led to disengagement.*
- *VCSEs working with women who had experienced trauma such as trafficking had an important role in encouraging their service users to engage with services as they often considered pregnancy a relatively minor event.*

- *VCSE approaches included: providing accessible information, helping women to understand the NHS system and encouraging engagement with services.*

As we have seen, expectations of being treated with prejudice and discrimination and the fear of being charged for healthcare can lead to disengagement from maternity services. There are also other ways in which expectations can impact on both care experiences and health-seeking behaviour.

Women in our focus groups told us about the differences between the NHS and other systems of maternity care. Sometimes, the comparison was favourable. One focus group participant talked about her very positive experiences of NHS maternity care and was very happy about the fact she had been seen by midwives, who 'gave good advice'. However, on further examination it transpired that the woman had booked very late, at six months, which appeared to be related to a very low expectation of maternity care. She told us *'In my country we don't have midwives. So, if a midwife comes and takes care of me, it's a real pleasure.'* Similar sentiments were expressed by a number of other focus group participants, who told us that the comparison with their home country made NHS maternity care seem very easy to access and made everything seem 'fine' by comparison.

"You know, back home there isn't midwives – you have to do it by yourself. You can't go to the hospital, they don't have the facilities over there. You have to give birth in your house."
(Focus group participant, Children's Centre, Birmingham)

[Translating for another participant] "She finds [accessing healthcare] absolutely easy. For her, where she comes from... it's a breeze here. It's the comparison isn't it? Where she comes from it's all so difficult. [Laughs]. That's why everything is fine."
(Focus group participant, translating for another participant, Children's Centre, Birmingham)

Another aspect that influenced women's engagement with maternity services was the expectation to be seen by a doctor, rather than a midwife. Some women did not believe that appointments with midwives were very important, because they did not carry out 'examinations'. In the focus group with Roma women from Poland and Romania, we were told that their expectations led some women to believe that they were not being given the proper level of care.

"Appointments with midwives, although there were multiple, they weren't that useful... The midwives didn't do any check-ups, examinations, and they were actually seeking another advice with the polish doctors, private health services, because then they knew more and were actually examined by the doctors.[...] The system in Poland is different. In terms of pregnancy you are mainly taken care of by a doctor."
(Translator, summarising discussion, Roma Support Group, London)

One of the VCSEs supporting women who had experienced extreme adversity such as FGM or modern-day slavery reported that these service users tended to have very low expectations of care during pregnancy. Encouraging women to attend appointments had become an important part of their work.

"Because we work with a quite diverse culture of women, some of them are of the opinion, especially if they have been trafficked or are seeking asylum, 'Why do we need to go to antenatal? I'm having a baby, it's no big deal.' So we have to re-educate them, because we want to make sure the baby is fine. So, we support them with that – attending antenatal and postnatal appointments."
(VCSE Community worker, Bethel Doula, Birmingham)

Breastfeeding - barriers and support

- There was a high level of knowledge about the benefits of breastfeeding in the focus groups and many mothers had been, or were still, breastfeeding.
- Barriers identified by women included lack of expertise and support in the clinical setting, preconceptions of younger mothers and negative societal and cultural attitudes.
- VCSEs expressed concern about staff training not being prioritised by NHS managers.
- Several women who faced difficulties with breastfeeding had been helped by support groups which they had accessed through hospitals or VCSEs.

Women from black and minority ethnic groups generally have higher rates of breastfeeding than non-minority ethnic women.⁷⁶ Many of the women we spoke to had been breastfeeding for long periods or were still doing so. Breastfeeding was discussed in very positive terms among focus group participants, highlighting both bonding and nutritional aspects.

⁷⁶ L. Oakley *et al.*, 2013, Factors associated with breastfeeding in England: an analysis by primary care trust, *BMJ Open*, 3(6): e002765. Available at: <https://bmjopen.bmj.com/content/3/6/e002765>

Overall, there was a high level of knowledge about the benefits of breastfeeding – in one parenting group we visited, it was part of the learning outcomes.

“Breastfeeding is the best, it is better than the bottle. It has your scent in it as well, and it’s healthy. And they will be bonded to you for a long time. They will know straight away it was from you.”
(Focus group participant, Sure Start Centre, Birmingham)

A significant number of the women we spoke to had experienced problems with breastfeeding or had wanted to breastfeed but not been able to do so. In terms of perceived barriers to breastfeeding, women identified a lack of expertise and support in primary and secondary care settings. Breastfeeding VCSEs echoed these sentiments and expressed concern about accredited breastfeeding training for health professionals being given low priority, due to overstretched NHS budgets.

“The nurse in the hospital who was supposed to have checked breastfeeding said I was feeding well and that everything was fine. But no, my daughter actually hadn’t eaten anything for those two days I was in hospital. When we came home, the health visitor noticed she had lost a lot of weight and sent me running off to buy formula. My daughter was a bit at risk, in that regard.”
(Focus group participant, Espacio Mama, Southwark)

“It was difficult. My daughter didn’t take the breast. She was premature. I went to the GP and said my baby’s not feeding. He said: ‘She doesn’t want it’. When I put the breast, she refused. So, when she was three months, she took the bottle. It was difficult – it was so painful! – The GP said: ‘She don’t like to suck.’”
(Focus group participant, Hackney Playbus, Hackney)

Another issue identified in the focus groups was prejudice towards young mothers and an expectation they would not breastfeed, leading to a lower level of support. One woman who had given birth to her first child in her early twenties and had her second child seven years later told us about two very different experiences – one negative and one positive. Another young mother told us about feeling undermined in her choices by unsupportive staff. She partially attributed this to stigma relating to having a mental health diagnosis, as well as her relatively young age.

“With my first, with breastfeeding, they didn’t help me at all. I was struggling and asking the midwife for help. She told me what to do but she didn’t seem that interested. She said: ‘You can give him a bottle.’ I gave up after a week. With this one, they helped me a lot so I’m still doing it. They told me about why I should breastfeed, because that’s the best way. They showed me how to do it properly.”
(Focus group participant, Hackney Playbus, Hackney)

“I felt very undermined by the midwives in the hospital. If she was crying, I was trying to breastfeed her, get her settled, they’d come and take her from me and try to give her a bottle. I was in tears, I was crying about doing a bad job. It made me question my own parenting. How am I meant to breastfeed my child if you’re taking her off me and trying to bottle feed her?”
(Focus group participant, Hackney Playbus, London)

Negative social and cultural attitudes to breastfeeding were mentioned by both focus group participants and VCSEs. One young mother who was still breastfeeding talked about feeling judged when feeding in public, stating: ‘You get a lot of bad attention.’ Women in the focus group for Gypsy and Traveller women told us that breastfeeding simply did not happen anymore in their community because of cultural attitudes and a lack of privacy in their homes.

“You do get judged for breastfeeding in a public place. People don’t like it. But my child needs feeding - she won’t take bottles and she’s got to eat, so... Thankfully she’s weaning now, so she’s eating food as well, but to settle her and get her to sleep – she wants me! You have a right to feed your child – it’s not against the law to breastfeed your child in public!”
(Focus group participant, Hackney Playbus, Hackney)

“Breastfeeding doesn’t happen in our community. You’re in this small space with no privacy and the men don’t want to see a woman like that in front of other men.”
(Focus group participant, FFT, Brighton)

The two breastfeeding organisations we interviewed echoed women’s concerns about public attitudes. They told us that, in addition to providing information, another function of their helplines was to give reassurance, moral support and encouragement to women calling. We were told that many women who called were fearful of being confronted by the public, or of facing the disapproval of family members, at time when they were feeling vulnerable and unable to deal with such criticism, with possible negative impact on their ability and willingness to breastfeed.

Several women who had initially experienced difficulties had been able to successfully breastfeed after accessing support in the community. Some of the women we spoke to had been referred to support groups by hospital staff, others had accessed support through VCSE community services.

“They didn’t help much in hospital, with my first baby it was very hard, and nobody to help me, I was very confused, very lost. But when I went to Beis Brucha Mother and Baby home [a postpartum facility for Orthodox Jewish mothers] they helped me. They helped me a lot there.”

(Focus group participants, Orthodox Jewish playgroup, London)

“I had trouble with the baby latching onto my breast, but I was referred by the midwife to a breastfeeding group where they taught me how to hold her. There are groups out there, when you need help.”

(Focus group participant, Hackney Playbus, Hackney)

Mental Health, Trauma and Abuse:

Mental health and wellbeing

- Many women considered monitoring and treatment for perinatal mental health to be inadequate. Barriers to disclosure included stigma, fear of social services involvement, the absence of established relationships with trusted health professionals and the expectation of poor treatment.
- Many women who had experienced infant death, stillbirth or late miscarriage had received inadequate emotional/mental health support, as well as inadequate or inaccessible information.
- VCSE approaches to support included: practical and emotional support during and shortly after birth and VCSE groups with a social component, such as mother and baby groups or parenting programmes.

Perinatal mental health - ‘They don’t ask how you are’

Pre-existing mental health problems are one of the main risk factors for perinatal mood disorders and the majority of VCSEs we spoke to said that their service users generally had poor mental health. Although clinical terms like pre-/postnatal depression were only occasionally used by focus group participants, many talked about ‘having a breakdown’, feeling ‘vulnerable’ and ‘emotional’ and ‘constantly crying’ during their pregnancies – descriptions that could be indicative of perinatal depression and anxiety or other perinatal mental illness, which affect up to 20% of women during pregnancy or in the first year after birth.⁷⁷ There was a general sense that monitoring and support to disclose problems in this area were inadequate – several women said they had never been asked about their emotional state by healthcare professionals at all during the perinatal period. One participant suggested that the monitoring form used by maternity services was an impersonal tick-box exercise, which needed to be complemented with allocated staff time to be effective and others agreed. Many of the sentiments expressed in focus groups are reflected in the 2016 National Maternity Review, which states in relation to mental health that ‘midwives must have sufficient time to have quality conversations with women before and after birth’ and emphasises the importance of continuity of carer to build up mutual trust.⁷⁸

“I think that if they see you’re very extreme, in a very extreme situation, then someone will take care of it. But if you’re in a bad way, but you don’t show it, they think you’re okay, ...

[Facilitator: But do they ask you at any point?]

They don’t ask you how you are.

They didn’t ask me anything.”

(Focus group participant, Espacio Mama, London)

Women told us that in the absence of obvious symptoms of severe distress, mood disorders would not necessarily be discovered or treated. A very small number of focus group participants appeared to have proactively sought help for a perinatal mental health problem. Reasons given included the absence of a trusting relationship with a known health professional and a prevalent fear of negative judgement from health professionals. Women from the Gypsy and Traveller community were especially concerned that a mental health diagnosis could lead to social services involvement and having

⁷⁷ A. Bauer *et al.*, 2015, *The costs of perinatal mental health problems – report summary*, Centre for Mental Health, LSE Personal Social Services Research Unit. Available at: http://eprints.lse.ac.uk/59885/1/_lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_Bauer%2C%20M_Bauer_Costs_perinatal_%20mental_2014_Bauer_Costs_perinatal_mental_2014_author.pdf

⁷⁸ National Maternity Review, 2016, *op. cit.*

children removed from their care. This sentiment reflects a wider fear of ‘authorities’ which is a known barrier to care and support for women in this community and their families.⁷⁹

“[It would have been helpful] just having a relationship with someone from the outs... Like a midwife who she recognises, she sees often, or a doctor who she sees and feeling confident enough to say, ‘all these feelings I’m feeling, is this normal? Should I be feeling like this?’ Because that’s a big thing – if you’re frightened to talk out because you don’t know how they’re going to meet you with answers, you know? You sometimes think, I shouldn’t... I won’t ask, because I don’t know what they’ll think about me.”

(Focus group participant, FFT, Brighton)

“If she’s feeling like she can’t cope, she is not going to say, ‘I can’t cope’. Because then she is going to think that social services is going to come in and take her baby away.”

(Focus group participant, FFT, Brighton)

The expectation of poor treatment from health professionals, for reasons relating to prejudice and discrimination and to language and communication barriers, came across strongly in several of our focus groups. These findings are concurrent with Maternity Action’s previous research on women’s access to primary care, which suggests that the expectation of prejudice and discrimination are barriers to support for women who are experiencing mental health problems.⁸⁰ As we have seen in a previous section, VCSEs also drew parallels between public attitudes towards these groups and their access to healthcare and support.

The emotional impacts of stillbirth and loss – ‘Nobody’s there’

Bereavement by miscarriage, stillbirth or neonatal death are associated with mental health problems in both mothers and fathers⁸¹ and the National Maternity Review acknowledged the need for ‘more support and better access over a longer term to counselling and therapy’ for families in this situation.⁸² Women who had experienced stillbirth told us about the profound impact on their mental health. Women said it was the worst thing to have ever happened to them and that it would stay in their minds forever. Several women expressed anger and confusion about how they had been treated by health professionals at the time of their loss, especially about having to go home and wait for up to a week, not being given enough information and not being offered any emotional or mental health support. One mother who had been through stillbirths or late miscarriage twice⁸³ said that the second time, it had been a ‘completely different experience’, in a positive sense, as the physical aspect had been dealt with straight away.

One woman had accessed counselling after a stillbirth, which was described as helpful. One woman said that the communication barrier may have caused her to miss out because she would not have known what the word ‘counselling’ meant at the time.

“You have to keep it one week, inside one week. I sit at home, I still feel something moving inside me, but I have to accept that, keeping the baby one week inside me, it was very hard experience.

It happened to me as well, same situation. Which is bad, when they announce to you that your baby died they have to do it straight away! But they have you go back home for a week! How are you going to feel?”

(Focus group participants, Children’s Centre, Hackney)

“[Facilitator:] Did you get offered anyone to talk to, counselling?”

No. They are always busy.”

(Focus group participant, Children’s Centre, Hackney)

“There’s no emotional support.

Nobody’s there. No one said to me, ‘It could be this,’ or, ‘How are you feeling?’ or, you know... It was nothing, it was: ‘Go home and come back on this time when the tests are back.’”

(Focus group participants, FFT, Brighton)

One young mother told us about the loss of her first child, who had been born prematurely with health problems and died at the age of one. She felt that she had been treated extremely poorly by the hospital in the aftermath, saying that ‘they couldn’t care less’ about her. Further, she said she had not been given enough information about the circumstances

⁷⁹ M. Jenkins, 2005, *No Travellers: A report on Gypsy and Traveller Women’s experiences of Maternity Care*, MIDRIS

⁸⁰ Maternity Action, 2014, *op. cit.*

⁸¹ Public Health England, 2017, *op. cit.*

⁸² National Maternity Review, 2016, *op. cit.*

⁸³ Women referred to ‘stillbirth’ and ‘late miscarriage’. We did not confirm gestational age of the foetus with focus group participants.

surrounding her child's death, meaning that it was still not clear to her exactly what had happened, which would have been likely to affect her mental health negatively, especially as she was already struggling with mental health problems at the time. No counselling or signposting to other support services had been offered in connection with her bereavement.

One community doula service for vulnerable mothers outlined the emotional and practical support provided to mothers and told us about supporting a mother who had recently lost a baby shortly after birth. The service, which is commissioned by the CCG, also links in with social workers and local mental health teams when service users are experiencing severe mental distress.

“At about 7 months they diagnosed that, once the child was born, the child wouldn't be compatible with life. They couldn't say 6 hours, 6 days. [...] The baby passed last night. So that is quite traumatic. We supported her through the last bits of her pregnancy, with all those complications. Obviously, that would affect her mental health and kind of general attitude to life... We are supporting by referring [to other services], providing that listening ear and that support, attending appointments with them, encouraging them to go to appointments and so on.”
(VCSE Community worker, Bethel Doula, Birmingham)

Accessing support after trauma, violence and abuse

- Domestic violence during pregnancy is one of the main risk factors for postpartum depression and one of the Adverse Childhood Experiences (ACEs) affecting children's health and wellbeing in later life.
- Stigma, fear of having children removed, widespread fear of authorities, expectations of prejudice and discrimination and a lack of knowledge of the support available were identified as barriers to help.
- Asylum seekers and other migrants face an increased risk of mental health problems and VCSEs highlighted the vulnerability of women with NRPF.
- VCSE approaches to support included: support with the application for lifting NRPF, flagging up abuse in casework, peer-support (sometimes pregnancy-focused) emotional and material help, information and advocacy.

Domestic Violence – ‘They are afraid to ask for help’

Domestic abuse affects one in four of all women at some point in their lifetime.⁸⁴ We know that abuse from a male partner often begins or worsens during pregnancy and that violence in the home during pregnancy is one of the main risk factors for postpartum depression.⁸⁵ It is also one of the Adverse Childhood Experiences (ACEs) that have been found to affect child health and wellbeing in later life and which can lead to a vicious circle of disadvantage if they are not addressed.⁸⁷ As has been mentioned previously, black and minority ethnic women are at increased risk of domestic violence. They also face some additional barriers to accessing support.

Six of the twenty VCSE organisations we interviewed named violence against women and girls (VAWG) as one of the main issues affecting their service users. Only one of these organisations specialises in supporting women affected by VAWG (specifically FGM). In the focus groups, violence and abuse were mainly spoken about in general terms, with few exceptions. In addition to the stigma associated with these issues, another possible explanation for their absence from most of our focus group discussions is that these behaviours are not always recognised as such by women. One VCSE provider told us:

“Within the initial crises and support meeting we do talk about domestic violence, and a lot of women will say, ‘No, I haven't experienced domestic violence’. When you ask them what their understating of domestic violence is, it's very limited. When you talk through the cross governmental definition, they are quite surprised it encompasses other behaviours, so actually the rates of women experiencing domestic violence are quite high, and we would flag that and support those women.”
(VCSE Community worker, Bump Buddies, London)

As was also the case with mental health, the fear of having children removed was mentioned as a barrier to seeking help for domestic violence. Other issues were a widespread fear of authorities and a lack of training and competence on

⁸⁴ Office for National Statistics, 2016, *Focus on Violent Crime and Sexual Offences, 2014/15*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/crimeandjustice/compendium/focusonviolentcrimeandsexualoffences/yearendingmarch2015/chapter4intimatepersonalviolenceandpartnerabuse>

⁸⁵ NHS Choices, *Domestic abuse in pregnancy*. <https://www.nhs.uk/conditions/pregnancy-and-baby/domestic-abuse-pregnant/>

⁸⁶ Centre for Disease Control and Prevention, 2016, *About Adverse Childhood Experiences*. Available at: https://www.cdc.gov/violenceprevention/acestudy/about_ace.html

⁸⁷ Prof. K. Hughes et al., 2017, The effect of multiple adverse childhood experiences on health: a systematic review and meta-analysis, *Lancet Public Health*, 2(8): e356-e366. Available at: <https://www.sciencedirect.com/science/article/pii/S2468266717301184>

domestic violence within the police force. Women who have experienced negative treatment from 'officials' may not consider the police to be a source of support, for example the Gypsy and Traveller women who described being forcibly evicted whilst pregnant, or women with insecure migration status who fear deportation or detention.

"Some women go through very bad domestic violence, but are afraid to ask for help, because they fear that the social services will come and take the children from them."
(Focus group participants, FFT, Brighton)

"Women are afraid of the police and the police are ill-prepared to deal with the issues faced by women, so they often end up re-traumatizing the victim, or make the victim out to be the perpetrator, or due to a lack of specialist support they put women in further danger."
(VCSE Community worker, LAWRS, London)

VCSEs highlighted how women with NRPF become trapped in violent situations as a result of their status, effectively 'falling between the chairs' in terms of the support available to them.

"Violence against women is a huge problem, especially if women do not have recourse to public funds and they are refused spaces in refuges."
(VCSE Community worker, LAWRS, London)

"Migrant women completely lose out on domestic violence services because of their status. They are not supposed to get homeless advice if they are no recourse to public funds. There has been an increase in that category where people just say, 'It's not our responsibility, we can't do anything.' These women cannot access support to get away from violent partners."
(VCSE Community worker, WAST, Manchester)

Dealing with trauma – 'Counselling changed my life'

The literature indicates that black and minority ethnic women from migrant backgrounds are at increased risk of mental health problems associated with severe trauma such as fleeing violence, being subjected to sexual abuse or undergoing torture, including Female Genital Mutilation.⁸⁸ Women in our focus groups told us that dealing with complex migration, asylum and associated issues also added to their mental stress.

One focus group participant told us that she had sought asylum in the UK on the grounds of protecting her baby daughter from Female Genital Mutilation (FGM), which she had also been subjected to. She said that she was living with 'constant stress', due to her situation and although the mother and baby group for vulnerable women, where the focus group was held, was a source of support, she told us that she also needed help with the asylum appeals process, which was at the root of her problems.

*"For me, when it comes to the stress, since I have my baby, I've been living with stress. When I had my baby, I was supposed to go back to my country, knowing that when I go to my country, my baby will undergo FGM. If I bring my daughter to my country... they think FGM leads to better health. [...] So it's just... having stress. If people call me, I can't even talk to them. You can't eat, you can't be confident. Everything."
[Facilitator:] Is there anything that helps you?
Right now, I'm waiting for my appeal. I don't have any help. I don't know what to do. I think this is about health because if I go back, it affects my baby's health...
[Facilitator:] So, this group – is it a support for you?
Yes, it releases my stress a bit, I socialise with people. Yeah, helpful for my condition. But my situation [...] I'm alone trying to stay here and protect my daughter here. "
(Focus group participant, Bethel Doula, Birmingham)*

Several focus group participants who had experienced severe trauma talked about how counselling and peer-support had helped them to move forward with their lives. Peer support emerged strongly as one of the main factors in health and wellbeing across most of our focus groups.

*"It has boosted my confidence coming to this group [REF's Strengthening Families Programme]. At first, it was the social worker who is involved with us who brought me to here. At first, I said no, because of my confidence and talking to people, and getting to know people. Then when I first came, with everyone, introduced myself. I was shy the first day, but then I just broke out and now I talk to everyone, get on well with everyone now."
(Focus group participant, Children's Centre, Birmingham)*

⁸⁸ FGM is recognised by the UN as a form of torture under the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment 1984 (United Nations, Treaty Series, vol. 1465, p. 185)

"We move our life, to another country. Everything is changed. Psychologically, sometimes physically... too much harm. It's not easy. You try to be better, and some people help us to be better. But before, when we came the first time... very difficult.

[Facilitator:] So who helps you to feel better?

Like, group of women when we come here. If you know some people, and you hear another story, you feel better, because you share your stories with people.

(Focus group participants, WAST, Manchester)

One young mother in a mother and baby group in Birmingham told us about the violence and conflict she had survived in her country of origin, losing her friends and family, which was still causing her to have nightmares or flashbacks. This woman spoke limited English, but had been able to access counselling along with an interpreter. She was now feeling more positive and appeared to have formed a strong, positive bond with her child. She told us: 'I'm happy with my baby, sometimes when I'm very down, he makes me happy.'

The focus group participant who had lost a child also described her struggle with mental health problems. There were multiple risk factors to her mental health, including parental drug addiction and childhood abuse. She told us that counselling had eventually been arranged for her by a concerned friend. The counselling was described as 'life-changing' helping her to move on, to the point where she rarely thought about the abuse. She now had three children, who in all likelihood benefited from this improvement to their mother's mental health.

As we have seen, many women find it hard to seek help for mental health and having advocacy or support with this is likely to play a positive role in women's access to treatment. VCSEs highlighted the need for advocacy as well as specialist counselling for women who may have little knowledge of the health system or whose needs are not well understood by mainstream health services.

"There is nearly a year's waiting list for specialist counselling around sexual violence in Manchester. First, they have to have the knowledge to go to the doctor and ask for the counselling, and then there is still the waiting list. You have to know your way around the health system. So, if you're worried about going to the doctor or if the health centre isn't being very supportive, you're not going to know that you can ask for counselling or approach the doctor about it."

(VCSE Community worker, WAST, Manchester)

The National organisation FORWARD – one of a small number of UK providers of counselling and other support for women who have undergone FGM – highlighted the combined challenges facing women who are dealing with the trauma of FGM and the stresses of the immigration system, in addition to the emotional and physical challenges of pregnancy and new motherhood. FORWARD expressed concern about the lack of funding for these services, saying that for many women, *'when they need psychotherapeutic intervention, there is none.'*

Socioeconomic and migrant status:

Poverty

- Poverty was frequently mentioned by women in various forms as one of the main 'issues affecting health and wellbeing', for example in terms of lifestyle and diet. VCSEs had seen a recent increase in food poverty. The Healthy Start scheme was highlighted as a positive factor.
- The majority of focus group participants recognised exercise as an important factor for health. Affordable options included social prescribing.
- VCSE responses included: food bank services and advice on entitlements to family-related benefits and statutory payments.

Low income and benefits

Issues around money came across strongly in various forms in all focus groups in response to the question about 'issues that affect health and wellbeing'. Many women told us they were struggling on very low incomes and several were having problems with their benefits and were facing possible eviction as a result. Housing issues are discussed in an upcoming section.

"I used to work as a hairdresser. I applied for the Maternity Allowance but they said I was on too low income before. So, they decided to pay me £27 / week..."

(Focus group participant, Hackney Playbus, London)

“She was given income support when she was pregnant, and then she had the child so it was about 18 months. Then they didn’t pass some test or assessment, because of that she also wasn’t receiving housing benefits and then she wasn’t able to pay the rent. It’s been months now – it’s a problem with the landlord. She went to the Job Centre to get Job Seekers allowance. There they also said they won’t accept her because she didn’t pass some test, or assessment. Now she has a small baby, she has to look for a job, and she is also the carer for her father...”
(Translator, Roma Support Group, London)

“Right now, in my case, I’m getting Maternity Allowance [...] that’s the only money I’m getting right now, a month. That money, we need to eat healthy, to get my vitamins... I spend all my money on just maintaining my healthy lifestyle.”
(Focus group participant, Hackney Playbus, London)

Low income and health – ‘It helps if you have resources’

VCSEs talked about seeing a recent rise in food poverty and said they were increasingly referring service users to emergency provisions such as food banks. Some VCSEs also operate their own food banks, enabling them to stock food items that suit their service users' needs.

“We are seeing more and more food poverty, food banks are great, absolutely fantastic. But if you are coming from a country where you never experienced carnation milk, or pasta, you may look at the food you have been given and not know what to do with it.”
(VCSE Community worker, Bump Buddies, London)

“[Some service users] get into debt or they’ve got no money to feed themselves or their children, so that’s where we come in and try and support with foodbank vouchers, referring them to soup kitchens and things like that.”
(VCSE Community worker, Bethel Doula, Birmingham)

With regards to healthy eating during pregnancy, focus group participants highlighted the difficulties of maintaining a healthy diet and lifestyle on a low budget. Several women, some of whom lived in temporary accommodation with little or nothing in the way of cooking facilities, also talked about the availability and visibility of relatively cheap but unhealthy fast food in their local area. The Healthy Start scheme, which provides vouchers for milk, fruit, vegetables and vitamins for pregnant women and mothers on certain benefits was mentioned as a positive factor affecting health. However, as one woman remarked, women who book late with maternity services miss out on the full benefits of this scheme.

“I am breastfeeding. I remember in the very beginning they keep telling you – you have to take vitamins. If you don’t have access to vitamins you can get them free. So, some mothers who maybe not until later get to see a midwife for whatever reason [don’t benefit from the scheme]. I was very late, because I was working.”
(Focus group participant, Hackney Playbus, London)

“You might want to live a healthy lifestyle, but if you don’t have the money to buy, for example, a good salad or fish or, I don’t know, salmon – it’s expensive – then you’d rather go and... I like chicken and chips because it’s like £1.99 or something, so it kind of helps if you have resources around you.”
(Focus group participant, Hackney Playbus, London)

Exercise is known to have positive impacts on both mental and physical health and although this was recognised by a large majority of focus group participants and mentioned frequently in terms of ‘factors impacting positively on health’, many women did not exercise regularly as they could not afford to join a gym. Solitary exercise was considered difficult to find motivation for and many women also lived in areas where they did not feel safe, which may have impacted on their ability to exercise outdoors. However, a few women had been able to access affordable options. A young mother who was living in homeless accommodation and had been experiencing a lot of stress during her pregnancy told us about accessing a gym through social prescribing from her GP. Another woman attended a leisure centre in Birmingham where anyone could exercise for free for an hour. A third woman was accessing an affordable exercise class specifically for Orthodox Jewish women in her local community.

Mothers without a safety net

- Many black and minority ethnic women from migrant backgrounds are unable to access the mainstream benefits system. Women who are able to access the alternative provision of the Asylum Support still face the health risks associated with poverty.
- Women with NRPF and their children are at increased risk of exploitation and abuse.

- Destitution was associated with stigma and mental stress for both mothers and children.
- VCSE responses included: support to access alternative sources of support, such as Section 17.

We know that a large number of black and minority ethnic women from migrant backgrounds experience extreme poverty and destitution but are unable to access the safety net provided by the mainstream benefits system. Some women in this situation can access an alternative system, which provides a very limited form of support. Others fall into destitution.

Asylum Support

Whilst mothers who qualify for Asylum Support⁸⁹ are provided with accommodation for themselves and their child (for example in a hostel) on a no-choice basis, as well as a small allowance each week on a payment card to be used for food, clothing, nappies and similar,⁹⁰ they subsist on a level below the poverty line and are therefore likely to be exposed to the associated health risks, such as poor diet, inadequate hygiene provisions and substandard living environments.

“...the asylum system, even if you are actually in it and receiving support, it’s a really tough system to be in, if you’re a family. It’s very difficult for women to make ends meet, to look after themselves properly, keep their mental health relatively in good shape and their physical health in good shape when they’re facing these incredible anxieties and pressures. Just the basics of having a roof over your head and being able to feed your children.”
(VCSE community worker, ASAP, London)

“They are only given £5 a day to live on. It’s difficult to have a good diet when pregnant. Poverty has an effect on her health and that of the baby. If one office doesn’t give her the money to live in the bed and breakfast, or if social services don’t link up with the bed and breakfast, she is potentially without food.”
(VCSE Community worker, WAST, Manchester)

In Maternity Action’s previous research with new mothers in this situation heard from a woman housed in Initial Accommodation with her newborn baby who was worried about hygiene, saying that she had to sterilise her baby’s bottles in a communal bathroom.⁹¹ Inadequate hygiene could pose a risk to a newborn baby who has not yet developed immunity. Similarly, women in our focus groups, who we know to be excluded from mainstream housing options, told us about the health effects of poor accommodation. This is discussed further in the section on housing.

No Recourse to Public Funds

Women who have no access to Asylum Support or benefits include those with the NRPF condition in their visa, for example women on a student or spousal visa. It also includes undocumented migrants who may have been trafficked into the UK, or had their visa invalidated when the relationship it depended on broke down, for example as a result of domestic violence.⁹² Women whose rights to reside are conditional on their relationship are often reluctant to seek help for domestic violence for this reason.⁹³ However, women who do seek help are unlikely to be able to access a space in a refuge as these are funded by mainstream sources. This is discussed further in the section on domestic violence.

Women and children who are excluded from both mainstream benefits and Asylum Support are extremely financially and socially vulnerable. If they are not allowed to work, mothers have few options to support their children. Mothers who are allowed to work find themselves excluded from the childcare support that is available to other working parents on low incomes.⁹⁴

“[Facilitator:] How do you see it manifest in terms of their health and wellbeing, when women have no recourse to public funds for example?
They become quite low, and depressed, and that then has a knock-on effect when they have the children, or it might affect their pregnancy because if they are not looking after themselves the unborn child is affected, or if they are abusing alcohol or drugs... they are born with withdrawal issues.”
(VCSE Community worker, Bethel Doula, Birmingham)

“The cost of child care is as much as their earnings, or more. NRPF affects mums as they are not entitled to free child care. So, it’s a catch 22 they literally can’t work enough hours to pay rent and feed the family.”
(VCSE community worker, Unity Project, London)

⁸⁹ Asylum seekers during their claim and certain categories of refused asylum seekers.

⁹⁰ Gov.co.uk, *Asylum support: What you’ll get*, <<https://www.gov.uk/asylum-support/what-youll-get>>

⁹¹ Maternity Action and Refugee Council, 2013, *op. cit.*

⁹² Maternity Action, 2017, *op. cit.*

⁹³ *Ibid.*

⁹⁴ NRPF Network, *What are not public funds?*, April 2018, <<http://www.nrpfnetwork.org.uk/information/Pages/not-public-funds.aspx>>

The desperation experienced by mothers in this situation was brought to life when one woman approached us after the consultation with asylum seekers, repeatedly asking if she could somehow be included in order to get the gratuity payment, telling us that she had no money and was 'desperate'. In another piece of research on charges for maternity care we also heard from destitute mothers with small children who told us they had not paid their landlords for months and who appeared to be extremely vulnerable to exploitation and abuse.⁹⁵

Destitution can have serious implications for children. In recognition of this, Local Authorities have the power to provide accommodation and financial support to families with 'children in need', even if they have no recourse to public funds, Under Section 17 of the Children Act.⁹⁶ It is also possible to get NRPF conditions lifted if a mother can prove that her financial circumstances are having an impact on the welfare of her children. However, specialist advice and support are often needed to access NRPF lift and Sec 17 support, which has given rise to specialist VCSEs that open up access to the system.

"The application itself to lift NRPF is really stressful. You need loads of evidence and documents and going to get that on top of working part-time, child care, etc. is it hugely stressful. Aside all the material things, the mental stress is very present. Every 2 ½ years having to make a new immigration application, and then every 2 ½ years having to re-make this change of condition application. It's pretty relentless, the mental stress of that."
(VCSE community worker, Unity Project, London)

ASAP provide free legal representation to asylum seekers who are appealing against the decision to refuse or remove their financial support and accommodation from the Home Office.

"At the tribunal there is no legal aid for representation, so if ASAP didn't exist providing the service then a lot of people would go unrepresented at the hearing."
(VCSE community worker, ASAP, National)

The stigma and stress of destitution – 'You can't look after your children the way you wanted'

Mothers and pregnant women in our focus group of women seeking asylum us about the stigma and stress of not being able to provide for their children in the way they would have wanted and the social effects on children of having a standard of life much lower than their peers. Impacts of this included; effects on their own and their children's mental health and wellbeing, children not being able to participate in activities and conflicts in school.

'My oldest son, he really gets upset in school, sometimes he needs to fight in school. Like if someone says, 'We have PS2, we have this, we have that.' He gets into fights, he can't get this, his Mum can't. Do you understand? He is always... it is really difficult.'
(Focus group participant, WAST, Manchester)

"You can't look after your children the way you wanted... Some of us who are single parents – children need it, we can't afford it! We are only given money to eat. It drives me crazy. Most of the days, I cry to sleep. Then I met one lady that brought me here. To this group, before coming here I was almost going [crazy]. We think children are supposed to be happy, they are not happy. When they go to school, and then we have to pay for school meal, I cannot afford it. And then they want to go to some kind of club..."
(Focus group participant, WAST, Manchester)

"Children want to do things, and we cannot pay. And then they are crying so it makes you feel bad as well. You can't provide for them. We don't have anything to do, we just have to continue. We have migrated, and then I think, just let me rest... It's not a good experience."
(Focus group participant, WAST, Manchester)

"My 3 children, I can't take them, for example, swimming. The older they get the more difficult it is. You can't do anything. Especially if you use the money to eat, for clothes. The need to wear shoes, they need to wear clothes. If you want to take them out, you don't have enough. You do all the shopping you have to do, then you have very little."
(Focus group participants, WAST, Manchester)

⁹⁵ R. Feldman, 2018, *What Price Safe Motherhood?*, Maternity Action [awaiting publication]

⁹⁶ Project 17, *Section 17 of the Children Act 1989 Factsheet*, May 2013, <<http://www.project17.org.uk/media/7763/s17-Factsheet-May-13.pdf>>

Housing and living conditions

- Unhygienic, cold and mouldy homes were linked to poor health such as breathing problems and skin complaints in children.
- Health and safety risks to pregnant women, new mothers and children included lack of access to hygiene facilities, broken wall sockets and a lack of fire safety provisions.
- Privately rented accommodation was associated with many problems for families with children, including the risk of eviction, overcrowding and the associated impacts on mental health and wellbeing. However, social housing was not considered a realistic prospect.
- Several mothers with young babies had been living in temporary accommodation for long periods. Associated problems included inadequate cooking facilities and social isolation.
- VCSE approaches included: housing and benefits advice provided by mainstream national and local specialist services.

'Hygiene matters when you're pregnant'

Numerous focus group participants across different cultural groups and with different kinds of migration status told us about unhygienic, cold, mouldy and unsafe homes. Living conditions were often linked to health problems in children. Women also talked about issues relating to hygiene and child health and physical safety. Children with breathing problems were reacting badly to damp and cold and a large number of mothers had problems with mice, damp, mould and poor insulation. Poor health and safety provision was another problem – one mother told us about sleeping in the basement with her baby during a house fire, not knowing what was going on upstairs.

"There are lots of mice in London. There's always some, in every house. And it's really hard to get them to sort those problems out for you. My husband puts out traps... but we can't use any poison with the kids around. And it's pretty disgusting because they run over everything."
(Focus group participant, Espacio Mama, Southwark)

"I have to put more clothes on the children in the house. It's cold."
[Facilitator:] *Do you think it affects their health?*
Yes, definitely. My oldest son, when it's cold he finds it difficult to breath. He has asthma. So, when the ground [floor] is too cold, I tell him to go up – I just have to manage him. It's not really too good for children."
(Focus group participant, WAST, Manchester)

"I am downstairs, underground. My room is really damp. Rubbish always on top of the window, which makes it dark. I can't open it, because there's something on top. There is a smell too. Under my wardrobe there are snails coming. The day before yesterday my baby was not breathing very well, I just called the ambulance and the lady who saw my baby said there is nothing at the moment for treatment but if you still stay in this place it will be bad for the baby. The air is not good for him. My body is itching, sometimes the body becomes red and once you start itching the body... I have all the evidence with me, we have mouse, cockroaches, all the things."
[Facilitator:] *How old is your baby?*
5 months. Last time there was a fire upstairs we heard screaming, all the smoke, but I didn't hear. Everyone was running outside, but me and my baby were sleeping downstairs. At that time, I don't know what I can do, it has been long time that I've been trying... I can show you the picture of the mouse, the cockroach..."
(Focus group participant, WAST, Manchester)

A focus group participant in the Gypsy and Traveller focus highlighted importance of access to showers and toilets on site during pregnancy and VCSEs talked about the link between accommodation, proper facilities and maternal and child health.

A lot of [health inequalities] has to do with poor accommodation, it is often sites situated near main roads, near rubbish dumps. That is if people have got somewhere legal to stop. So, there is a chronic shortage of accommodation in the country, it's like 25,000 people actually have nowhere to live. For those people, there is no access to running water, or toilets. So, if you can imagine for a pregnant woman, on a site, on an unauthorized encampment... things like urinary tract infections are really common because women might have to wait for someone to take them to the toilet."
(VCSE community worker, FFT, Surrey and Sussex)

Privately rented accommodation and the risk of eviction – ‘You don’t know when you will end up on the streets’

The majority of women who talked to us about housing were living in privately rented accommodation (with the exception of Gypsy and Traveller women who were all living on Traveller sites). A substantial number were also living in temporary homeless hostels or Home Office accommodation.

Renting privately was associated with high cost, ‘rough landlords’ and the risk of eviction, as well as a lack of control over their situation. However, the general consensus was that social housing was extremely difficult to qualify for, so was not seen as an alternative.

“They said basically the hope to get social housing is very low. They are also advised by different advisors even not to try because they know that the success rate will be very, very low.”

(Translator summarising focus group participants’ discussion, Roma Support Group, London)

Apart from the impacts on physical health, which have been mentioned previously, poor living conditions and the threat of homelessness are also associated with stress and anxiety,⁹⁷ which, as we have seen, have negative impacts on pregnant women, mothers and their children. Women expressed frustration and helplessness over the fact that landlords had no incentive to make improvements or keep rents reasonable as tenants could easily be replaced. One single mother in our focus group with women from the Roma community was facing possible eviction with her five children between the ages of 1 and 17, after the application of the benefit cap meant she was no longer eligible for housing benefit and had been unable to pay her rent. She worried about ‘ending up basically on the streets’ with her children. One woman expressed her lack of control in terms of ‘just having to sit there and smile’ if she should be evicted.

“[Housing benefit] has gone through, but really not the right amount. We reapplied and it’s taking a very long time.

[Facilitator:] So, is it causing you problems?

Yes, it is. I have to pay the rent with it.

And if she doesn’t, she has a problem. The landlord doesn’t have an issue –they just find the next person!

They kick you out.

[Facilitator:] Have you ever been told that you had to leave?

Loads of people have, sure!

I have, that’s why I’m now in [area]. I have four children. Our landlord gave us three months’ notice

You just have to sit there and smile and say ‘OK.’”

(Focus group participants, Orthodox Jewish playgroup, London)

“It worries you. You don’t know when you will end up basically on the streets. Because the housing said if I make myself intentionally homeless they can’t help me... I don’t know if she will evict me, I have a contract until May. I don’t know what the landlady will decide to do. I have five children. The oldest one is 17, and the youngest one year.”

(Focus group participant, Roma Support Group, London)

Focus group participants highlighted the difficulties of having a family whilst in insecure tenancies, as private landlords can put restrictions on families with children, narrowing the options for mothers. One mother told us about hiding her children from her landlord. She said ‘it was the only way I could rent somewhere.’

“Moving house is a lot more difficult when you have kids. Because some of them say to you--. You go to view a place and they say, ‘You have kids but we don’t accept kids.’ So, moving somewhere else and getting them to rent you a flat is complicated.”

(Focus group participants, Espacio Mama, Southwark)

Overcrowding – ‘There’s just one room for an entire family’

VCSEs and focus group participants in London talked about overcrowding due to high rents and the impacts on relationships, and on health and wellbeing for both adults and children, for example relating to illnesses spreading between family members but also the stress of not having enough privacy and of constantly monitoring children in order to safeguard them and keep them from entering other tenants’ living spaces.

⁹⁷ Mind, 2014, *The Mind guide to housing and mental health*. Available at: https://www.mind.org.uk/media/1624759/guide-to-housing_2014.pdf

*"Housing can cause relationship problems. It can cause problems for the children because they are unhappy in these crowded environments. And when someone has flu, everybody has flu."
(VCSE Community worker, JuMP, London)*

"It's so expensive and for a family with kids, well it's difficult to rent an apartment for just your family. We end up having to share a flat and there's just one room for an entire family. So that's not good for your health because you can't relax, because you have to keep an eye on your children to make sure that they don't go in another room or make too much noise or because there might be people who you don't know coming and going. So that's as bad for the children as it is for the adults..."

[Facilitator:] And do you think that that affects the kids too?

Of course. I mean, I think it's harder for the children than it is for the adults. Because the adults know what's allowed or whatever, but that's really hard for the kids to know."

(Focus group participant, Espacio Mama, Southwark)

Participants in our focus group with Orthodox Jewish women told us they were all 'living in small spaces', but that they had little option but to stay in the local area because of their religious and cultural needs. Mothers highlighted the importance of having communal facilities such as parks and playgroups, for their children to be able to get fresh air and exercise, as they generally did not have gardens. However, both the VCSE we spoke to and the women in the focus group, which was held at an Orthodox Jewish playgroup at a local Children's Centre, said they preferred community-specific services and smaller groups.

"For the two weeks of the summer we go away, all my kids have their own bedroom, it's a dream. Here they are all sleeping in one bedroom... and they are so excited. And it's just two weeks, and they come back and it's the anti-climax. It's very hard, we come back to our cramped house."

(Focus group participant, Orthodox Jewish playgroup, London)

"We have to be together, because of religious purposes we need support, we need our schools. We can't branch out too far, because on a Sabbath we don't drive – I don't know how we would go about..."

Basically because of our religion... We are Jewish, we can't drive on a Saturday or use any vehicles, so we have to be walking distance from the Synagogue, because we pray three times on a Sabbath, so we have to stay near, within walking distance, of a Synagogue.

During the week also, because of the schools. You can't live too far from the school, and the shops."

(Focus group participant, Orthodox Jewish playgroup, London)

Homelessness and temporary accommodation – 'All through my pregnancy I was crying'

Mothers who were living with their young babies in homeless hostels told us about the effects on their health and wellbeing, relationships, diet and mental and physical health. Women talked about the mental stress of living in temporary accommodation for long periods with no end in sight. They also highlighted the social effects of not being allowed visitors, with likely negative impacts on the paternal relationship, as well as being socially isolating for the pregnant woman or new mother – a known factor in postpartum depression. One mother told us about not having a safe space for children to move around, with possible impacts on their physical development. Another had been separated from her five-year old child as a result of being in temporary accommodation whilst pregnant and told us she had spent most of her pregnancy crying. Physical health issues associated with temporary accommodation included not having sufficient cooking facilities or food storage spaces and having to climb flights of stairs when recovering from a caesarean section.

Three women in our focus group at a playgroup in Hackney in London talked about their experiences of living in temporary accommodation.

[In response to question: What are the things that affect your health, in either negative or positive ways?]

"Negative is that I live in a hostel. Just being left in the lurch not knowing how long it's going to be and whether your case is going to be accepted into the system. So that's one aspect. Not being able to have visitors is depressing, just staying in the room... But [partner's family] are just down the road, so I can go and visit. Their first language isn't English so sometimes it's a bit hard to communicate with them. But it's nice to be able to take her out to play and get her development, because in the hostel in the room, it's not big enough for her to crawl around.

[Facilitator:] Do you feel like it's safe for her?

Not really. One scenario is that I've got a broken wall socket and I've waited months for them to come and fix it and they still haven't, so it's not the safest of places. We've been there a year and half.

I'm in the same situation!

[Facilitator:] Has it taken you away from the people you know?

It's taken me away from my son, my older son. He has to live with my mum now. He's seven years old. All through my pregnancy I was crying. I was so tempted to just go to my mum's house but I decided to wait and see what happens. I've been there two years.

I'm in the same situation as well. Since I was pregnant. I have a two-month old baby. I am not allowed visitors. Just me and the baby. I have to go outside to see people. And since the C-section, to go outside the building I have to take the stairs. It's not good for me. When the father came to see the baby, we had to stand outside on the steps.

[Facilitator:] So, the baby's father is not allowed to visit you where you live?

No. We sit on the stairs.

[Facilitator:] And do you think that affects the relationship between the father and the baby?

Yeah. I've been there six months."

(Focus group participants, Hackney Playbus, London)

Community and social support – 'No one should be left alone, suffering'

- Community belonging was linked to emotional wellbeing and stress relief as well as practical support.
- Some women said they would not feel comfortable attending 'mainstream' perinatal services. This could form part of the explanation for lower levels of engagement with pre and postnatal services in some black and minority ethnic communities.
- VCSE approaches included: specialist provision of a range of perinatal services, geared to the needs of a local community.

The cultural community was generally described as a source of practical and emotional support and social activity.

"[Facilitator:] Can you think of any other things around you that affect your health?

The community. You live in different community. Pakistani, Somali – we've all got different cultures...

Some areas have a very good community. The community can affect you very positive. You enjoy your life, you remain active, you don't have any stress when you are part of the community.

[Facilitator:] Is there an aspect of, for example, getting help with your children?

Yes. If your community is supportive, they can look after your child."

(Focus group participants, Children's Centre, Birmingham)

However, another aspect of being part of a close-knit community was that women were less likely to be attending mainstream services, such as antenatal classes. One VCSE we spoke to told us about a range of antenatal services specifically for Orthodox Jewish women in the local area that had been developed for this reason, including antenatal classes and pre and postnatal mental health support. Focus group participants in the Orthodox Jewish playgroup that we visited told us about a network of services that they knew about or had engaged with, some of which were accessible through their Synagogue.

"We have an organisation called Bikur Cholim. They gave me nurses to help look after the baby, my baby was nine months and I broke my hand, so I couldn't even change his nappy. So, they gave me nurses the whole time and they gave me money."

(Focus group participant, Orthodox Jewish playgroup, London)

"There's lots of [organisations for Orthodox Jewish women] a few of them, there's an abuse one, any one suffering any type of abuse can call. So, no one should be left alone, suffering. If anyone's had a miscarriage, a loss, there's a lot of services out there. Also, there are numbers to call. And even during our pregnancy we have classes, we have a very good team of support."

(Focus group participant, Orthodox Jewish playgroup, London)

We know that pregnant women from black and minority ethnic communities are less likely to attend antenatal classes.⁹⁸ This may be attributable to a lack of culturally appropriate provision. The majority of women in our Roma focus group told us that they had not attended any such classes. Orthodox Jewish women and the VCSE we spoke to that supported this group told us there was a preference in the community for special classes.

"[Facilitator:] would you like to go to a mainstream class? Like a mainstream antenatal class?

I want to go with people I know. Small, private classes."

(Focus group participant, Orthodox Jewish playgroup, London)

⁹⁸ J. Henderson, M. Redshaw, 2017, Sociodemographic differences in women's experience of early labour care: a mixed methods study, *BMJ Open*, 7(7): e016351. Available at: <http://bmiopen.bmj.com/content/7/7/e016351>

VCSE approaches to social and economic factors - Networks of holistic support

- The presence of a social support network was mentioned in terms of the positive effects on maternal and child health and wellbeing, both mental and physical. Attendance at social groups helped with confidence and with bringing down stress levels.
- VCSEs supporting seldom heard communities emphasised the importance of being rooted in the community in order for the bridging function to work effectively, requiring a substantial investment of time and resources.
- VCSE approaches included: a wide range of practical, emotional and legal support functions, in recognition of the complex interaction between social factors and health inequalities and the multitude of challenges facing many women.

We know that social support is an important factor in maternal and child health and wellbeing, in terms of both mental and physical health and that loneliness plays a role in premature death. Focus group participants accessing holistic services talked about them as a positive focal point in their lives, where they could get support with anything from emergency food provisions in some cases, to advice about breastfeeding in others. For some women, the VCSE service would be the only source of social support they had.

[Facilitator:] When you have problems with money, housing... where do you go?

[Collective:] Here!

A place like this, if the Home Office rejects your claim, and you feel depressed, or if you need help financially. Sometimes they give us food, so they really help us a lot here. A solicitor came today and gave free legal advice.”
(Focus group participants, WAST, Manchester)

“[T]hey know that every Friday there is a group by them and for them in central Manchester. That becomes their base almost, because most of them haven’t got a base, haven’t got a family.”

(VCSE Community worker, WAST, Manchester)

“We talk about it in the [REF Strengthening Families] course. All about giving birth and breastfeeding and how to look after babies when they are born.”

(Focus group participant, Children’s Centre, Birmingham)

VCSEs providing peer support and advocacy told us about the networks of organisations they could draw on to provide ‘bridging’ support to service users with issues outside of their own area of expertise. However, for this to be effective, VCSEs needed to be seen to be trustworthy and have strong foundations in the community, requiring substantial investment of time.

“We have a 24-hour helpline [for Orthodox Jewish women] and I take about 10-15 calls a day on a voluntary basis about anything from physical or emotional issues during pregnancy, complications, postnatal support, breastfeeding... anything, including financial problems or wanting to stay longer in hospital or having had a bad experience in hospital. Women trust me, so I can advocate for them, or I know where to signpost them to.”

(VCSE community worker, JuMP, Hackney)

“You need to front load, you need to spend a lot of time building up trust with people, you need to provide answers, resources, at the point when people need it, if you are going to get that buy-in. It’s real community development, it’s starting where people are at and going that journey with them. I’ve been here long enough now to see a change, so we’ve got people that I knew as kids are now young mothers, so the intergenerational stuff is making a change. It was interesting to hear that they all got their own immunizations for example, 15 years ago that would not have been the case.”

(VCSE Community worker, FFT, Surrey and Sussex)

Several VCSEs expressed concern that organisations in their networks were disappearing, saying ‘Sometimes there isn’t another organisation I can refer the mum to too, because that has closed its doors.’

Pregnancy and maternity at work – ‘I didn’t want a big drama’

- VCSEs outlined the health impacts of maternity and pregnancy discrimination and poor treatment at work, including mental stress and potential health effects of not attending maternity care appointments.
- Barriers to accessing support with pregnancy and maternity discrimination included ‘not wanting to cause trouble’, lacking the resources to invest in the tribunal process and not being able to wait long periods for compensation.

- In some cases, late booking was associated with not being granted time off to attend antenatal care.
- Poor health and safety conditions were associated with financial impacts when pregnant women were pushed into going on sick leave instead of being given alternative duties.
- VCSE approaches included: provision and signposting to specialist advice on pregnancy and maternity rights at work and the information and support provided by unions.

Focus group participants talked about poor treatment at work in conjunction with pregnancy and the impacts on their lives. One focus group participant told us about being passed over for training and promotion opportunities because of her pregnancy and maternity leave and returning to find a junior colleague whom she had trained had surpassed her in rank due to attending the training in her place. She felt that she had been treated unfairly because she was pregnant. She said 'it was a big slap on me'.

One mother had delayed her booking appointment until 23 weeks, as her employer did not allow time off for this. The employer had then refused to pay when she went on maternity leave, but although she had found out that she had a case, the woman decided it was not worth pursuing, not wanting to 'make a big drama and dispute'. The same woman also said that she had delayed motherhood for several years in order to keep her job. She regretted both of these things, saying: 'People should be confident to use their rights, because that's why they are there.'

I could have gone to court. I knew my rights but I didn't want to attempt this forever, just to get my money from my employer, which I'm entitled to, because they told me: "You can dispute it, but it can take up to a year."
(Focus group participant, Hackney Playbus, London)

Evidence from VCSEs suggests that the above is not an unusual scenario, given that pursuing a claim against an employer requires a lot of resources.

"It's only really women who can pay for legal advice and representation that would have any hope in successfully bringing in employment tribunal, because there is plenty of research that shows that women who bring their own claim are far less likely to succeed at a tribunal. There are considerable challenges in helping and supporting women to deal with problems at work during pregnancy and maternity leave, even women who have quite blatantly been dismissed or pushed out of their jobs there is really only limited support we can give them, and then if they can get further help, and legal advice and take it to tribunal will depend if they have the resources."
(VCSE Community worker, Maternity Action MRAL, National)

Although trade unions are able to help with anything from signposting all the way up to representation in an employment appeal tribunal, we were told that many women lacked awareness of their rights at work, and that they could get support with pregnancy and maternity related issues from their union.

"Often workers will see a trade union as being there for when it is a problem about pay, or accident. But 'I can't get time off for my ante natal appointment' is a massive issue for our members. We want to reach out to women and say, 'This is a trade union issue'. The other one is getting an appropriate and timely risk assessment. Women aren't getting appropriate and timely risk assessment when they need it, and they aren't aware of their right to a risk assessment, what it is, or what it should involve. Another is, when a risk assessment is carried out, and it reveals a need for lighter duties [...] very often employers will put pressure on them to go off sick, which potentially impacts their entitlement to SMP. That happens quite a lot, that women are being pressured to go off sick."
(VCSE Community worker, USDAW, National)

VCSEs outlined some of the impacts they had come across when supporting women with maternity and pregnancy discrimination and poor treatment at work. These included the potential health effects of not attending maternity care appointments, the mental stress of facing managers who may have treated them very badly and the fear of job loss and loss of income. They told us that women often put up with bad situations, as all this stress was not compatible with the demands of new motherhood.

"It's very difficult to be able to anything about it when you are a new mother. You don't have time, it can be very hard to attend employment tribunal hearings with a baby, you might not have anyone who can hold the baby for you for example. The reality of the tribunal services nowadays is that you will have to bring your case yourself, so who is going to look after the baby while you stand up and argue your claim for maternity pay? Or discrimination in the employment tribunal? So I think that is putting a lot of people off, of really dealing with the issue. Along with concerns about losing their jobs, of they create too many waves [...] they can't afford to be seen as trouble-makers. Which is a massive concern, as sometimes they are left in dangerous, nasty, bullying situations. It's not that they can't physically do anything about it, but they feel they can't, without risking too much."
(VCSE Community worker, Southwark Law Centre, London)

"Even if they have a good claim, the way they have been treated, the thought of having to stand up in an employment tribunal and face their boss, and tell with it, on top of a new born baby, sleeplessness and all those

worries, it's just not going to seem worth it, and my fear with pregnant women is that a lot of them are just going to decide it is not worth the effort. Even when they have been very badly treated. The more able and articulate ones might be able to negotiate something, get a settlement [...] but the ones in the bottom, the cleaners and zero-hour contracts are so vulnerable. And employers know that, and definitely take advantage of that.”
(VCSE Community worker, Southwark Law Centre, London)

Health and safety at work

VCSES told us that the inability to challenge employers on health and safety issues and appropriate working conditions during pregnancy could have many long-term effects on women's lives, both health related and financial.

“It affects women's earnings, it affects the level of their maternity pay, so that's already having a huge impact on the family income, a huge impact women's stress levels, it can affect their health if health and safety issues at work are not dealt with, we get many women that are very concerned that it will cause bleeding during pregnancy, many callers concerned about miscarriage, and also become very concerned about their job security because they feel it's so unpleasant and unwelcoming that they might just leave. And the employer then doesn't have 'hassle', as [their employers] see it of employing them throughout their pregnancy.

[...]

For many women, because they can't get their employer to make what are often small changes, like allowing them to go to the toilet a bit more often, have somewhere to sit down, or for instance for carers or nurses to no longer do heavy lifting or being in contact with violent patients. It can often mean they are forced to take quite long periods of sick leave during their pregnancy, and that has a huge impact on women, as many are only entitled to statutory sick pay, which is £80 per week so their earnings drop in the middle of their pregnancy, that affects their maternity pay, it means they will get much lower maternity pay than they would otherwise, or they miss out on their maternity pay completely and have to claim maternity allowance from the Job Centre Plus.”
(VCSE Community worker, Maternity Action MRAL, National)

Part 4 – Local practice examples

The following local practice examples are based on the twenty interviews we carried out with selected VCSEs in our organisational networks. Organisations were chosen based on their geographic location, service user group and specialism in order to include a wide range of generalist and specialist organisations as well as VCSEs supporting specific seldom heard communities. In lieu of the formal evaluations or return on investment analyses that smaller grassroots and community groups with limited resources often do not have, VCSEs were chosen on the basis of qualitative evidence, such as service user feedback and organisational reputation.

Maternity Action: Maternity Care Access Advice Service

This service provides telephone, email advice and casework to women from abroad on how to access NHS maternity care and issues associated with charging for NHS care. The women contacting the Maternity Care Access Advice Line include migrants, refugees, asylum seekers and British women who are returning to the UK to settle or visit. The service also provides advice to advisers and midwives.

The service promotes access to maternity care for pregnant women and new mothers who are unsure how to obtain care, who are fearful of NHS charges or who are directly affected by charging. It seeks to reduce the number of women who delay commencement of maternity care, miss appointments or avoid care all together. The service is funded by philanthropic trusts.

Salford Citizens Advice Bureau: Expectant Families Advice

Salford residents who are pregnant or who have had a baby in the last three months are referred to the specialist Expectant Families Adviser to provide them with a full range of information on benefits, housing and debt in a single one hour advice session, with a follow-up information package sent to them afterwards. The service is funded under a health funding stream (originally from the CCG, now from the local authority), in recognition of the health impacts of housing and income. Service users are commonly on low incomes and face difficulties in meeting their basic needs, such as suitable accommodation and food. The session focuses on awareness of entitlement to Maternity Pay and/or core benefits, as well as initiatives like Healthy Start or the Sure Start maternity grant. The majority of referrals come from gateway advisers at Salford CAB branches.

Bethel Health and Healing Network: Doula Service

The Bethel Health and Healing Network provides doulas who support disadvantaged women referred by agencies, midwives, doctors and friends. Support takes place from pregnancy through to three months after the birth. Doulas visit the women where they live and provide support on the basis of need, including breastfeeding support, emotional support, home support, as well as identifying issues surrounding domestic violence, FGM and modern slavery. Doulas are key in explaining the importance of attending ante- and post-natal check-ups to women who may be used to different healthcare systems. They also accompany women to appointments.

The service addresses issues regarding mental health, lack of a support network and social isolation. After the three-month period, women are able to attend a mother and baby group for continued support. Service users are vulnerable migrant women who are refugees or in the asylum process, or who have no recourse to public funds as well as vulnerable British women. The service is partly funded by Sandwell and West Birmingham and South Central CCGs.

Women Asylum Seekers Together (WAST)

As a user-led peer support group for women seeking asylum, members provide each other with emotional support and empower one another by sharing their knowledge and experiences, as well as taking part in campaigning to raise awareness of the issues they face.

The health and wellbeing of pregnant women and mothers who are WAST members is affected by multiple issues, including poverty and destitution – often receiving as little as £5 a day as their asylum support - race, poor housing, dispersal, language barriers, and isolation. The service provides them with a space to meet, share experiences and emotionally support one another, at their weekly drop-in in central Manchester. WAST also has a food bank and invites legal practitioners to sessions to give free legal advice.

Race Equality Foundation: Strengthening Families, Strengthening Communities

Strengthening Families, Strengthening Communities is a group-based parenting programme, open to all parents of babies, children and young people from birth up to 18 years old. The programme consists of three hour sessions delivered once a week for 13 weeks. The course addresses a range of issues around parenting, trying to support the participants with their individual needs and concerns as well as consider issues that may arise in the future; exploring the role of being a parent and the context in which their family is functioning. This involves equipping parents with strategies for behaviour management, solution building, developing warm and resilient parent child relationship and enhancing communication, both with members of their own families and with relevant professionals outside of the home.

The programme was designed to engage those parents who are hardest to reach and who weren't participating in mainstream family support and parenting service, with 50% of participants from BAME communities and over 60% having a household income of £10,000 or less. Both mums and dads are welcome, however around 85% of attendees are women. Mental health and wellbeing is the most commonly raised upon referral or during the groups, and is most often articulated with reference to depression, anxiety, isolation and a lack of confidence when parenting. One of the issues facing SFSC facilitators is making sure there are appropriate services to signpost/refer those parents in need of further support to during delivery or once the 13-week course ends.

Manor Gardens: Bright Beginnings Perinatal Programme

The project covers the London boroughs in Islington, Camden and Haringey, however women in Home Office accommodation or who are homeless can also be referred, even if they are outside these areas. It provides support to vulnerable migrant women during the perinatal period, until the child's first birthday. Many of the women being supported by the project are facing poverty and destitution, as well as poor housing, a prevalence of domestic violence, health conditions and mental health issues such as anxiety, depression and PTSD.

At the core of the project is breaking language barriers. There are five bilingual maternity mentors speaking: Arabic, Bulgarian, Czech, Kromati, Kurdish, Portuguese, Russian, Somali, Spanish and Turkish, offering one-to-one support to around 100 women at any given time, such as accompanying them to hospital appointments, organising baby things and helping them apply for benefits. They also organise bilingual workshops, with the aim of raising awareness about how the health and benefits systems work and the importance presenting early for maternity care. In addition, a volunteer-led Perinatal Peer Support project has been established in Camden, to tackle isolation and which is open to both mothers and fathers.

Bump Buddies

Part of the Shoreditch Trust social enterprise, Bump Buddies works to support vulnerable women residing in Hackney through two main core services: crisis support and peer-mentoring. The women referred to the crisis support service are visited by Bump Buddies in their home, where an assessment is made and they are signposted to other organisations. Some of the challenges Bump Buddies will help women tackle are related to poor housing, chargeability, as well as language barriers when accessing health services. Bump Buddies continues to support the women by liaising with other organisations, and maintaining a relationship with the women throughout. The mentoring programme matches women who are pregnant with other Hackney mothers who have been trained and DBS checked, for support during the pregnancy. At any time, there are approximately 10 on-going mentoring relationships. This support can be varied, and its scope is negotiated between the mentor, mentee and the mentoring officer at Bump Buddies.

Jewish Maternity Project (JuMP)

JuMP is a maternity program for Orthodox Jewish women, working closely with residents of Hackney. It offers ante- and post-natal care and support for mothers of the community, through a wide range of classes, breastfeeding support, as well as targeted assistance to matters relating to mental health and social exclusion. The CCG funds a number of antenatal classes for specific communities and JuMP provides these classes for Orthodox Jewish mothers. JuMP is deeply rooted in the community and has a strong relationship with the local hospitals.

Unity Project

The Unity Project, based in North London, supports families in making their 'No Recourse to Public Funds lift application', also known as 'change of conditions applications'. These applications are long, and bureaucratic requiring a lot of details related to the families income, housing, health and can take an emotional toll on the service users. Families work with the organisation at the weekly drop in, and approximately three or four weeks are needed to complete an application. Each week the Unity Project sets 10 weekly appointments, having the majority of their referrals from organisations in Hackney and Haringey.

The Unity Project seeks to support families who are destitute or facing destitution as a consequence of having support removed, to access the help they need to negotiate the complex NRPFLift application process.

Southwark Law Centre

Southwark Law Centre in London provides legal advice to people who would otherwise be without representation due to financial constraints. Service users with complex issues needing specialist advice are referred by other VCSE organisations such as the Citizen's Advice Bureau.

The employment adviser at Southwark Law Centre provides legal assistance to many women who have experienced unfavourable treatment at work and are facing the mental stress of pursuing a work related grievance during pregnancy or new motherhood. The Law Centre opens up access to the legal system to service users who would otherwise be unable to seek legal redress and helps them to gain knowledge about their rights.

USDAW

USDAW is the Union of Shop, Distributive and Allied Workers. It is the country's 5th largest trade union with a membership that, to a large extent, consists of women on low incomes working in one or more physically demanding part-time jobs with insecure hours.

USDAW raises awareness about women's rights at work and support them to access these rights, including the right to a risk assessment during pregnancy and the right to continue breastfeeding after returning from maternity leave. USDAW works to ensure that pregnancy and maternity are seen by members as trade union issues for which they can access support and aims to equip them with resources to deal with maternity and pregnancy discrimination and unfavourable treatment, for example by providing a standard letter that women can use to request risk assessments from their employer.

Association of Breastfeeding Mothers

The Association of Breastfeeding Mothers offers a peer-support service for breastfeeding mothers as well as two national helplines, one of which is delivered jointly with the Breastfeeding Network. All of the support provided is accessible by BSL and Language Line. The Association of Breastfeeding Mothers also delivers training on breastfeeding for professionals.

The organisation aims to overcome the cultural attitudes that result in lower rates of breastfeeding in the UK by working with both women and frontline health professionals. ABM seeks to help women overcome the limits to their choice imposed by negative attitudes, as well as addressing the isolation that arises when women feel they are not supported to follow through on their choice to breastfeed. It also seeks to improve awareness amongst midwives and paediatricians of ways to support ongoing breastfeeding, rather than encouraging a swap to formula milk, and encourage open channels of communication around breastfeeding even where the healthcare professionals' advice is not in line with the wishes of the mother.

The Breastfeeding Network

The Breastfeeding Network aims to provide evidence based information to women and healthcare professionals and to boost confidence around breastfeeding. It provides a joint advice line with the Association of Breastfeeding Mothers which is open daily and gives advice in a number of community languages. The organisation works with communities where breastfeeding rates are low, through a network of volunteers and accredited peer-supporters. It also seeks to challenge negative attitudes to breastfeeding on a wider scale. Drop-in breastfeeding support groups are provided locally, offering regular face-to-face support, some of which are subject to funding or part of a commissioned local project to support a local area's strategy to support breastfeeding.

FORWARD

FORWARD is a campaign and support organisation that works holistically with women and girls mainly from Africa, who are experiencing trauma such as FGM, child marriage, domestic abuse and trafficking. Projects include community health champions, multi-agency support in partnerships with hospitals and specialist counselling. FORWARD is also funded by London councils to provide resources for schools on violence against women and harmful practices. There is also a free legal advice clinic and a telephone advice service.

FORWARD aims to ensure that pregnant women who have undergone FGM get the appropriate care and support with their mental, physical and social health by providing one-to-one support in partnership with a number of hospitals across the UK. This includes being present during healthcare appointments, providing emotional and language support. It also means helping women who may be destitute and subject to NRPFLift and living in temporary housing in poor conditions to

access any financial support available to them. The organisation also helps service users who have experienced severe trauma and may have PTSD to move forward with their lives by providing specialist counselling or by linking women with the appropriate service.

Maternity Action: Maternity Rights Advice Line

The Maternity Rights Advice Line provides a generalist telephone advice on maternity and parental rights at work and entitlements to benefits to around 2,000 callers each year. This covers information on maternity/paternity/shared parental leave and pay and protections from maternity discrimination, as well as entitlements to child benefits, tax credit and the Sure Start Maternity Grant.

The advice line provides guidance to women facing difficulties at work during pregnancy, maternity leave and return, such as refusals to grant paid time off for antenatal appointments or failure to take health and safety considerations seriously. By informing women about their rights and entitlements so that they can be more confident in their dealings with employers and the benefits system, the Maternity Rights Advice Line helps address mental and physical health problems, such as increased levels of stress in the perinatal period or the lower levels of income and maternity pay that are a result of being forced to take sick leave during a pregnancy. The service is funded by philanthropic trusts.

Maternity Action: Migrant Women's Rights Service

Maternity Action's Migrant Women's Rights Service is a second-tier advice line for paid workers and volunteers in the VCSE and statutory sectors who are supporting vulnerable migrant women who are pregnant or new mothers. The service is particularly targeted at midwives and VCSE advice staff. The advice line enables professionals and volunteers to help migrant, refugee and asylum seeker women who are experiencing problems relating to income, housing and access to maternity care, by providing tailored advice through email and phone. Furthermore, the service also builds capacity with midwives and voluntary sector workers to help women tackle these issues. This is done by providing free training courses and seminars to midwives and voluntary sector works across the UK, as well as a range of online information sheets.

Project 17

Project 17 provides advocacy to families who are subject to NRPF conditions. Many of their clients are pregnant women. Project 17 runs an appointments-based service where families are assessed for their ability to access Section 17 support under the Children Act. Where this is the case, they are supported with the process, including sometimes being accompanied to meetings with the Local Authority. They also do policy work and help other organisations to build capacity.

Project 17 aims to improve access to Section 17 support for a growing number of clients who struggle with increasingly restrictive legal environment, in terms of accessing accommodation and bank accounts and who struggle with court fees. By doing so, the organisation aims to alleviate the many problems faced by families who experience homelessness and destitution, which tend to include mental and physical impacts.

Asylum Support Appeals Project (ASAP)

ASAP provides free legal representation to asylum seekers who are appealing against the decision to refuse or remove their financial support and accommodation from the Home Office (Asylum Support). Representation at hearings is provided by staff team and volunteers. Referrals come from other UK VCSEs, such as the Red Cross. ASAP also has a telephone advice service. A large proportion of ASAP's clients are single mothers.

ASAP opens up access to legal representation to clients who would otherwise go unrepresented at their hearing as there is no legal aid for this. Families who come to ASAP are either destitute at the time of the hearing, or facing having their support removed and being placed into a situation of destitution. ASAP aims to help families keep a roof over their heads and the ability to feed children.

Latin American Women's Rights Service

LAWRS is an organisation run by Latin American women for Latin American women who migrate to London, with the aim of supporting them in accessing benefits, healthcare, education and employment protections. It also runs immigration and family law advice services, as well as domestic and sexual violence support.

LAWRS attempts to raise awareness of the particular issues faced by Latin American women in light of their limited visibility as a group, due in large part to the lack of an appropriate category on demographic data forms for the 200,000+ Latin Americans in the U.K. It also helps women to overcome situations where they are trapped in violent relationships and exploitative jobs, as a result of the requirements of the current benefits system or because they are subject to NRPF conditions.

Friends, Families and Travellers (FFT)

FFT is a national membership organisation for Gypsies and Travellers which was started in 1994 in response to the Criminal Justice and Public Order Act, which had a big impact on traditional ethnic travellers. FFT undertakes local casework in Sussex, Surrey and Kent and brings evidence from the community into policy, including on national level. FFT projects include health outreach, cultural awareness training, health advocacy and doula services, under a wider community development umbrella.

FFT aims to support women and families in the Gypsy and Traveller community to have better health by addressing a multitude of barriers to health and healthcare. The cultural awareness courses for health professionals challenge the damaging stereotypes which underpin prejudice and discrimination. FFT also supports service users to develop health literacy and provides accessible information materials. The organisation is deeply rooted in the community, with half of staff being from Gypsy or Traveller background and also has a specialist community doula who advocates for women in Gypsy, Traveller and Roma communities, including new arrivals in the UK, who may struggle with literacy and language barriers. The doula service links women in with maternity care and other health services, but also with other support such as advice on NHS maternity care charges.

Part 5 – Recommendations

Based on the literature review and the findings emerging from our consultations, we make the following recommendations:

National policies

1. The Home Office, the Department for Health and Social Care, the Department for Education and the Department for Work and Pensions (DWP) should incorporate assessment of health impacts on pregnant women and new mothers from diverse ethnic backgrounds and their children, into their policy processes in relation to asylum support, Section 17 support, social care, housing benefit and other benefits that form part of the social safety net against destitution and homelessness.

Improving local service delivery

2. Sustainability and Transformation Partnerships (STPs) Integrated Care Systems (ICSs) and Local Maternity Systems (LMSs) should invest in the development of community development skills, locating this within their system as part of their approach to co-production and co-delivery of services with local VCSEs.
3. Commissioners and NHS organisations should develop an understanding of local VCSE assets in relation to identifying and signposting vulnerable pregnant women and new mothers from black and minority ethnic backgrounds with mental health issues and consider supporting organisations carrying out this role through training and local knowledge-sharing.
4. Commissioners should fund VCSE organisations working with low income BME women to build capacity and expertise to link women with statutory services through bridging, signposting and advocacy.
5. Commissioners should explore strategies to support local VCSEs to better demonstrating their impact, recognise the limited resources of local VCSEs and the costs of undertaking effective evaluations.
6. Commissioners should ensure that interpreting and language services are available to low income BME women accessing health services and that the models of language support used reflect local needs.
7. Commissioners should ensure that place-based approaches accommodate the needs women who move between places, including: Gypsy and Traveller women with a traditional nomadic lifestyle; dispersed asylum seekers who are moved at short notice on a no-choice basis; and homeless women living in temporary accommodation.

Improving local commissioning

8. Commissioners should ensure that information about migrants in JSNAs is disaggregated by gender as well as ethnicity or nationality and that information about women takes note of their migration situation, as this affects access to health and other services.
9. Commissioners should recognise the resource implications for VCSEs of collating information for the JSNA process. Commissioners should provide funding and/or practical support to enable VCSEs working with low income BME women to research the needs of seldom heard communities and feed this into the JSNA process.
10. Commissioners should facilitate asset based commissioning by engaging with the VCSE sector through existing local infrastructure such as CVS, local and regional social prescribing networks and Healthwatch and to support the development of such infrastructure.
11. In order to include smaller VCSEs who may lack capacity to deliver large scale public sector contracts, commissioners should consider a variety of approaches to procurement, including grant funding and alliance contracting.
12. Commissioners should consider joined up approaches to service delivery across 'silos' (i.e. CCGs and Local Authorities) in order to support families using maternity and community services.
13. Commissioners should work with VCSE sector organisations in their local area in order to identify and address training needs in the local workforce.

Appendix 1: Consent and confidentiality form

Service User Focus Group



Information for participants

This focus group is part of a research project that Maternity Action is working on with the Department of Health, Public Health England and NHS England, about the health and wellbeing of pregnant women, mothers and their young children and how it can be improved.

We are doing eleven focus groups in the UK, asking women to share their thoughts about things that affect their health. The information and insights we gather will be used by the NHS in their work on preventing poor health, as part of the Maternity Transformation Programme.

Participant consent and confidentiality form

- I have read the **Information for participants and understand** the purpose of the research project and agree to take part in a focus group.
- I understand that I may withdraw from the research project at any stage.
- I understand that while information gained during the study may be published, I will not be identified and my personal results will remain completely confidential.
- I agree that the focus group will be audio-recorded.
- I understand that written notes of the focus group will be stored securely and any recording of the focus group will be destroyed.

Signed (research participant)

Print name Date

Signed (focus group facilitator)

Print name Date

Appendix 1a: Spanish language consent and confidentiality form

Grupo Focal con Usuarías de Servicios



Información para participantes

Este grupo focal es parte de un proyecto de investigación en la cual Maternity Action trabaja con el Department of Health, Public Health England and NHS England (órganos estatales de salud en Inglaterra) sobre el temática de la salud y el bienestar de las mujeres, madres y sus hijos pequeños y como se puede mejorar el nivel de estos.

Estamos haciendo once grupos focales con mujeres alrededor de Inglaterra, invitándolas a compartir sus opiniones y experiencias sobre las cosas que les afectan la salud. El NHS (Servicio Nacional de Salud) va a usar la información y los conocimientos que juntamos en sus esfuerzos para prevenir la mala salud, como parte de su Programa de Transformación Materna.

Consentimiento y confidencialidad de la participante

- He leído la **Información para participantes** y entiendo el objetivo de este proyecto de investigación y acepto participar en este grupo focal.
- Comprendo que me puedo retirar de este proyecto de investigación en cualquier momento
- Entiendo que, aunque se puede publicar la información obtenida durante el estudio, yo no seré identificada y mis respuestas particulares quedaran completamente confidenciales
- Doy mi consentimiento para que graben el audio del grupo focal
- Comprendo que se guardaran en un lugar seguro los apuntes escritos del grupo focal y se destruirán toda grabación del grupo focal después de haber sido transcrito.

Firma (participante)

Aclaración Fecha

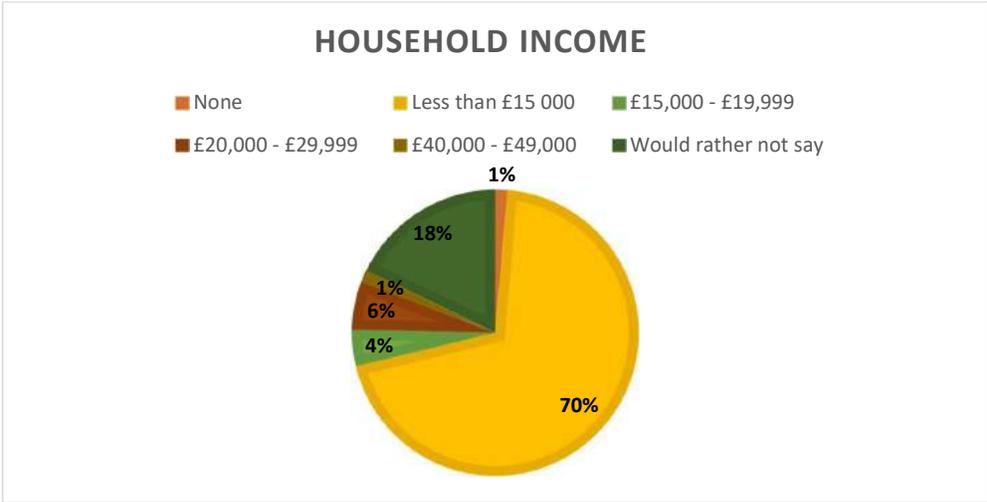
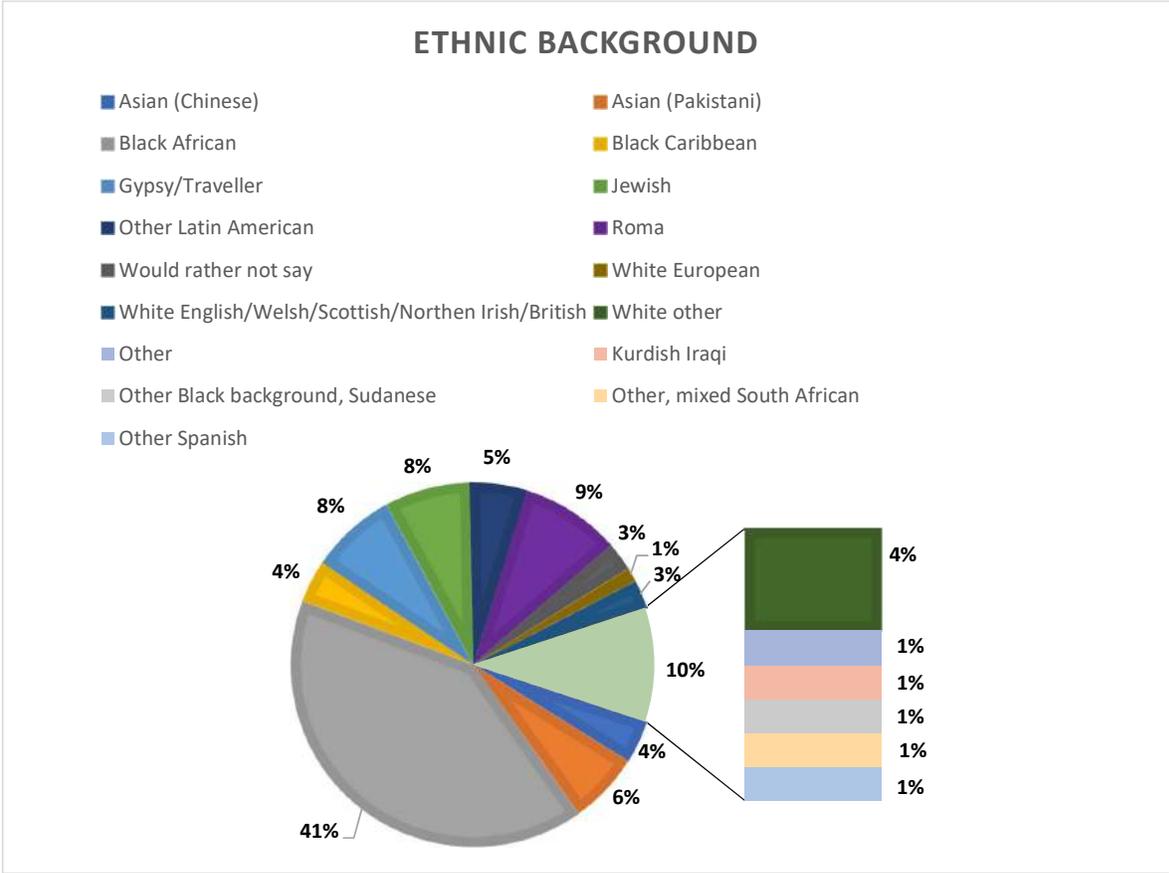
Firma (facilitadora del grupo focal)

Aclaración **Fecha**

Appendix 2: Focus group host organisations

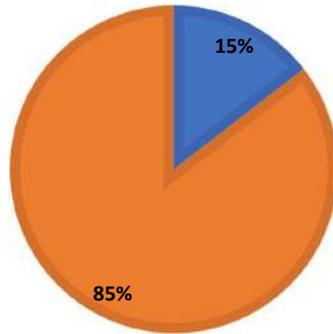
Community partner	Location	Service Users
Bethel Doula	Birmingham	Vulnerable mothers, mainly migrants
Friends, Families and Travellers	Sussex/Surrey	Gypsies and travellers
Golden Hillock Children's Centre	Birmingham	Mainstream service
Hackney Playbus	Hackney	Vulnerable mothers
LAWRS/Espacio Mama	Southwark	Latin American mothers
Morningside Children's Centre	Hackney	Mainstream service
Roma Support Group	Hackney	Roma
The Triangle Children's Centre	Haringey	Mainstream service hosting a playgroup for Orthodox Jewish mothers
WAST	Manchester	Women asylum seekers, mainly from Africa

Appendix 3: Focus group demographics



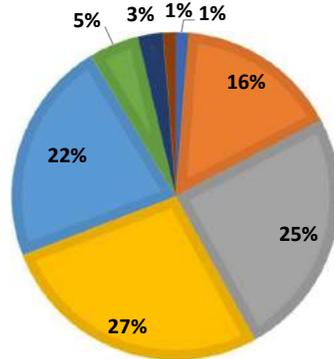
CURRENTLY PREGNANT?

■ Yes ■ No



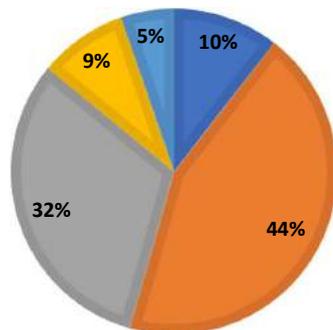
AGE IN YEARS

■ Under 18 ■ 19-25 ■ 26-30 ■ 31-35 ■ 36-40 ■ 41-45 ■ 46-50 ■ 51-55



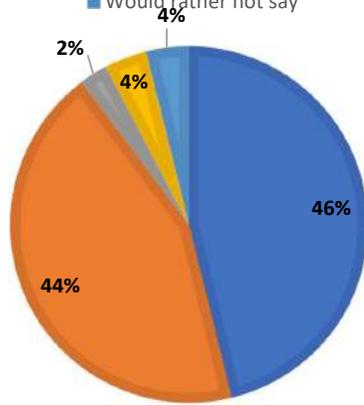
FORMAL EDUCATION

■ Primary ■ Secondary ■ Further ■ Higher ■ None



HOUSEHOLD

■ Single with children ■ Couple with children ■ Couple no children
■ Other ■ Would rather not say



Appendix 4: Focus group discussion items

1. What does 'good health' mean for you? – Please consider both mental health and physical health.
2. Do you find it easy or difficult to live a 'healthy lifestyle'?
3. What are the things that affect your health, in both positive and negative ways?

[Discussion then framed around topics raised and how they contribute to good/bad health, ex.]

Themes likely to emerge and potential follow-up topics:

Work

- Income
- Quality of work environment.
- Health and safety.
- Precarious work.
- Discrimination.

Money

- Benefits (incl. asylum support, where relevant)
- Sharing of money within household

Housing

- Heating
- Energy bills (being able to cook)

Pregnancy

- Booking (~10 wks)
- Regular attendance at midwife
- Antenatal classes
- Screening and immunisation
- Exercise (access to facilities, money, time / childcare)

Diet

- Help to lose weight/eat healthily? What kind of things would help?

Folic acid and prenatal vitamins.

- Did you take them? Where did you find out about them? Could you afford them?

Smoking

- Help to quit?
- Alcohol and substance abuse

Relationships / social life

- Supportive / unsupportive relationship with child's father. Please describe his involvement/relationship with the child/ren? Do you think there is anything that can be done to encourage and support the father-child relationship?
- Was father/partner involved during the pregnancy? Accompany to appointments? Emotional support? Present during birth? Do you think there is anything that would have encouraged him to be more involved?

Relationship problems / domestic violence? What kind of things are needed to support good relationships?

- Social support from family or others
- Social activities (both adults and children)

Mental health

- Perinatal mood disorders:
- Postnatal and pre-natal depression and anxiety
- Were you affected by this?

[If yes – did you also experience emotional difficulties *before* your pregnancy? Did healthcare professionals pay specific attention to this when you became pregnant?]

- Did you let anybody know? (Did midwives / health visitors /GPs ask?)
- Did you get help? Medicine/talking therapies/both? (Interpreter at counselling)
- Is there enough help?
- Would you have preferred anything to have been done differently?

Access to care

- Have ever been told you had to pay for maternity care? Been sent a bill from hospital?
- Do you experience a language barrier when accessing healthcare? How do you deal with this?
- Do you feel that healthcare professionals communicate clearly and that you understand them?
- Other potential barriers: time off work, childcare, stigma around mental health, prescription costs, etc.
- Low expectations of professionals

Advice

- Where do you go if you have problems at work, problems with money, housing, benefits or legal issues?

Contraceptive and reproductive health

- Access
- Choice

Children's health

- Prematurity and low birth weight
- Breastfeeding. Support?
- Screening and immunisations
- Postnatal care
- Transition to health visiting / early years

Appendix 5: Organisations interviewed about local practice

	VCSEs and Organisations	Location	Service Users
1	Association of Breastfeeding Mothers	National	Breastfeeding women
2	Asylum Support Appeals Project	London	Migrant Women
3	Bethel Doula	Birmingham	Vulnerable migrant mothers
4	Bright Beginnings	Islington, Camden, Haringey	BME migrant mothers
5	Bump Buddies	Hackney	Socially isolated mothers
6	FORWARD	Birmingham, London	African women
7	Friends, Families and Travellers	Sussex/Surrey	Travellers, Gypsies
7.1	Friends, Families and Travellers Doula	Sussex/Surrey	Travellers, Gypsies
8	JuMP	Hackney	Orthodox Jewish mothers
9	LAWRS	Southwark	Latin American migrant women
10	Maternity Action, Maternity Care Access Advice Service (MCAAS)	National	Migrant women
11	Maternity Action, Maternity Rights Advice Line (MRAL)	National	Mainstream advice service
12	Maternity Action, Migrant Women's Rights Service (MWRS)	National	Second tier advice and training for those supporting migrant women
12	Project 17	London	NRPF migrants
13	Race Equality Foundation	National	BME people
14	Roma Support Group	National	Roma people
15	Salford CAB	Manchester	Mainstream advice service
16	Southwark Law Centre	Southwark	Mainstream advice service
17	St Basil's	Birmingham	Young homeless people
18	The Breastfeeding Network	National	Breastfeeding women
19	Unity Project	London	NRPF migrants
20	USDAW	National	Union of Shop, Distributive and Allied Workers
21	WAST	Manchester	Women asylum seekers, mainly African

Appendix 6: VCSE interview questions

1. Name and job title of person being interviewed.
2. Please give some background about the organisation or project.
3. What kind of support do you provide to pregnant women and new mothers and how is it delivered? (I.e. legal advice over the phone, breastfeeding peer-support visits).
4. Who are your service users (i.e. demographics)? Do you have any exclusion criteria?
5. What are the main issues affecting the health and wellbeing of the mothers and pregnant women you support, and their children?
6. What are the main challenges to you as an organisation?
7. Is there anything else you want to add?