

13 THE MOTHERS WHO DIED: SOCIAL DETERMINANTS OF MATERNAL HEALTH

Before the early twentieth century death in childbirth was both common and indiscriminating. From the impoverished mothers in the workhouses of Victorian England, through those who worked in fields, factories or shops, to the comfortable well-to-do and even the aristocracy, all women were at risk of the big maternal killers of the time such as infection, bleeding and toxæmia (high blood pressure of pregnancy and eclampsia).

The development of modern obstetrics and midwifery and the introduction of legal abortion markedly changed this. The tide of deaths from these Direct obstetric conditions, which can only occur in pregnancy, has receded and now most mothers die from Indirect causes. These are usually pre-existing medical or mental health conditions which, although not directly due to pregnancy, are adversely affected by the changes pregnancy brings. Thus conditions such as heart disease, epilepsy and psychiatric ill health account for much larger proportions of maternal deaths than they used to. And these Indirect deaths are also far commoner in women with underlying physical or mental health issues and who may be socially vulnerable in other ways.

The social factors

Adverse social factors which can affect pregnancy include poverty, deprivation, minority ethnicity, limited English language and refugee status. Lifestyle factors such as drug and alcohol misuse, poor nutrition and obesity also have harmful effects. Mothers and their babies are also severely affected by domestic abuse or by people around them who limit their autonomy and control their access to care. Examples of this include trafficked women, 'mail-order' or underage brides and women living with the effects of genital mutilation or cutting.

These findings pose the question of how such avoidable inequities can be identified, reduced and eventually eliminated. It is well known that apart from receiving high-quality clinical care, key determinants of maternal well-being are care early in pregnancy and regular check-ups. Efforts have been made to make services more accessible, but much of what is needed to address the

underlying issues lies far beyond the scope of the health services. This problem needs to be addressed through coherent, coordinated action by national and local government departments, agencies and stakeholders.

Victorian attitudes to women's health

Inequalities in women's health have existed for centuries. Deaths in pregnancy, one of the greatest killers of young women, tended to be overlooked and regarded almost as an occupational hazard, while studies of men's health have a long history. In the 1830s Edwin Chadwick, whom some regard as the father of modern public health, found a 15-year difference in life expectancy between better-off men and those of working age in the poorer parts of London, and showed that this was due to overcrowding, poor sanitation and infection. His work eventually led to the 1848 Public Health Act with legislation for street cleaning, sewage and clean water. His plea for indoor toilets, however, was not heard until after the Second World War.

Even though deaths in childbirth were still shockingly common, and despite the growing interest in health inequalities, the focus in the first part of the nineteenth century remained resolutely on variations in death rates among men. It took a woman to change this. Once she returned from the Crimea, Florence Nightingale turned her pioneering statistical gaze on the number of deaths among women giving birth in workhouses and the charitable 'lying-in' hospitals (Figure 13.1). Better-off mothers tended to give birth in the relative comfort of their own homes, attended by a physician or obstetrician. In 1872 Nightingale calculated that 'for every 2 women who died delivered at home, 15 must have died if delivered in a lying-in hospital'.

The deaths were mostly due to sepsis, which spread rapidly in public facilities due to poor hygiene. Deprivation, poverty, the stigma of illegitimacy and other adverse life circumstances had led these women to deliver in such places. But Florence Nightingale was aware that mothers at home were also at high risk of dying, and she also asked, 'why is it that, at home, 1 out of every 128 must die? If the facts are correct, then one cannot help feeling that they present a very strong *prima facie* case for inquiring, with the view of devising a remedy for such a state of things.' She would have welcomed the advent of the Confidential Enquiries into Maternal Deaths (CEMDs).

Fact-finding begins

By the start of the twentieth century the high maternal mortality rate had at last become a matter of major public and professional concern. The highest death



Figure 13.1 Florence Nightingale (1820–1910) argued for major reforms and professional training for all staff caring for the ‘sick poor’ and is regarded as the founder of modern nursing and midwifery practice. However, not everyone was enthusiastic and many members of the medical profession were hostile to her ideas. A number of anonymous doctors writing in the *British Medical Journal* accused her of ‘having a kind, womanly heart’, ‘sublime simplicity’ and being ‘purely sentimental’.

rates in the country, in Rochdale, outnumbered London rates by nearly 10 to 1. Initially it was suggested that this difference was due to the effects of malnutrition or the poor working environments in the mills. In 1929, however, a detailed confidential enquiry, the first of its kind, showed the main factors to be a lack of antenatal care, limited healthcare knowledge in the general population and poor clinical care. The action taken on these findings led to a dramatic decline in the local death rate within five years, the first real example of evidence-based improvements in maternal care. It laid the path for similar enquires to start elsewhere, ultimately resulting in the national Confidential Enquiry in 1952 (see Chapter 2).

During the 1930s national reports on maternal mortality started to include short paragraphs on the wider social circumstances of the mothers who died. This was an achievement in itself because data collection systems were in their infancy, the National Health Service (NHS) did not yet

exist and it was only possible to collect basic information such as a mother's age, marital status and perhaps her previous pregnancies. Nonetheless, all of these reports identified that, when compared to southern England, maternal death rates were three times higher in South Wales, the 'Black' country of the manufacturing Midlands and some industrial cities of the north.

The urban mothers who died tended to have been poor, lived in overcrowded tenements and depended on charitable and highly stretched health services, whereas those in rural areas faced an almost entire lack of maternity services. In one report mention was made of 'racial' differences between these areas, but data on ethnic groups were not collected so presumably this related to other social characteristics of the women.

The reports of the 1930s also first described the variation in the availability of antenatal or hospital-based obstetric facilities within a reasonable distance of the mother's home, this being a crucial determinant of health – although sometimes in unexpected ways. One author blamed the high rural maternal death rate on 'the building of hundreds of little cottage hospitals' where low-quality caesarean sections were performed by staff with little obstetric expertise.

The early Enquiries, 1952–1994

In 1952, when the Confidential Enquiries started in England and Wales, statistics showed that, infection aside, mothers still died more frequently in Wales than in England, and that, within England, maternal mortality rates remained higher in rural areas. Apart from this the reports that covered the first 40 years of the Enquiry (which by 1994 had grown to include Scotland and Northern Ireland) contained virtually no information about the social circumstances of the mothers who died. Age and the number of previous pregnancies were the only indicators routinely available, and it was already known that older and more parous mothers were at higher risk of complications and death.

The first CEMD report, for 1952–4, did attempt to use marital status and wealth (presumably guessed at by the assessors) as indicators for the mothers who died from abortion, but not for deaths from other causes. Successive reports contained only tables on marital status, presumably as a proxy for some form of social characteristic, but all this showed was an increase in births outside marriage over the following years. The report for 1988–90 eventually concluded that 'being unmarried was not a risk factor for maternal mortality overall'. This has remained so ever since.

The Black Report and the resurgence of the public health movement

By the 1970s it was becoming clear that it was untenable to assume that the NHS, left to its own devices, would eventually eliminate health inequalities. The resurgence of interest in and expanding literature on inequities and their links to the social determinants of health led, in 1977, to the Labour government asking Sir Douglas Black, an eminent professor of medicine and ex-president of the Royal College of Physicians, to chair an enquiry into this.

His report showed what many had suspected: not only did the poorest people still have the highest rates of ill health and death, but the gap was widening. Although the 'Black Report' considered maternal deaths only in passing because the numbers were relatively small, it found that rates were at least doubled in women of the lowest occupational group, unskilled workers, compared to the professional classes (Figure 13.2).

The Black Report's publication in 1980 was essentially suppressed by the Conservative government. Only 260 photocopies were ever made available – to selected media contacts on a bank holiday Monday. But far from the facts being suppressed, the touch paper was lit. The authors held their own press conferences, after which there was a public outcry followed by a rapid resurgence of the public health movement and advocacy for 'health for all'.

But nothing was actually done for another 10 years, when inequalities became the subject of other nationally commissioned reports, notably by Sir Donald Acheson and also *The Health of the Nation*, a government report published in 1992 as a response to the World Health Organization's (WHO) *Global Strategy for Health for All by the Year 2000*. Presumably for lack of data, none of these UK reports looked at differences in health outcomes by ethnicity. Nonetheless they all came to the same conclusion: inequalities could not be ignored or wished away.

1990: A question mark over the need for the Enquiries

During the first 40 years of the Confidential Enquiries, inequalities were barely mentioned, even following the Black Report. The great successes of the CEMD's early years were largely due to improvements in clinical care and legislation for safe, legal abortion. Through the development and implementation of clinical guidelines and other improvements, by the early 1990s the United Kingdom had arguably one of the lowest maternal death rates in the world. As a result, within the government and among other commentators, questions were being asked about why the Enquiries should continue. After all, it was

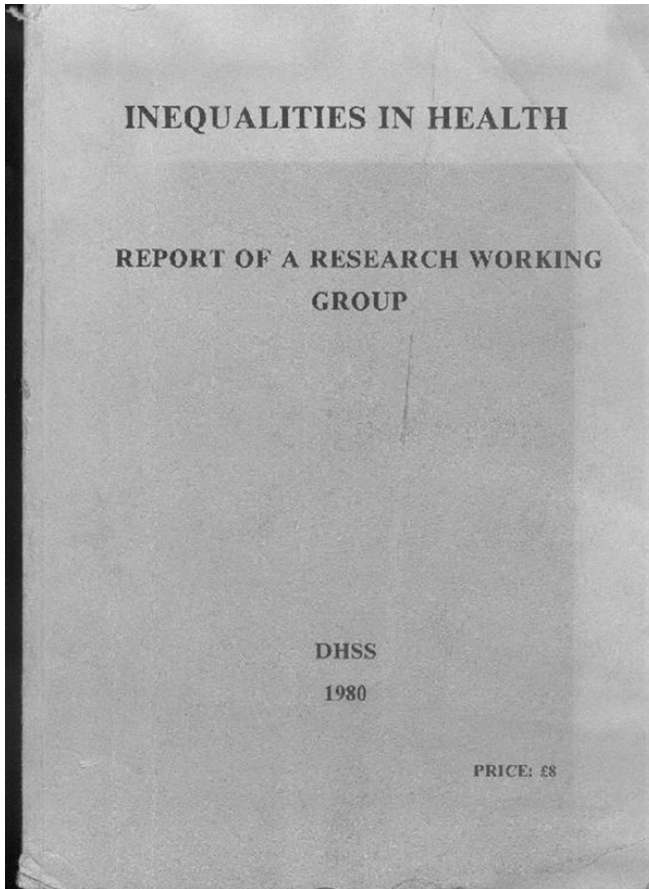


Figure 13.2 The Black Report (1980). In its foreword Secretary of State for Social Services Patrick Jenkin stated, 'It will be seen that the Group has reached the view that the causes of health inequalities are so deep rooted that only a major and wide-ranging programme of public expenditure is capable of altering the pattern. I must make it clear that additional expenditure . . . is quite unrealistic in present or any foreseeable economic circumstances, quite apart from any judgement that may be formed of the effectiveness of such expenditure in dealing with the problems identified.'

argued, the number of women dying from pregnancy-related causes had probably reached 'an irreducible minimum'.

This thinking has proven seriously mistaken, partly in its dismissal of the prospects of further advances in clinical care, but also in ignoring growing public concerns about equity and the possible social determinants of poor maternal health. Fortunately, enlightened Department of Health officials eventually decided not only to save the Enquiry but to extend its scope and

appointed a public health physician as the Department of Health's new director, with an expanded assessment panel and an editorial group composed of the most respected professionals.

A new kind of Report: Why Mothers Die, 1994–1996

While continuing with the existing agenda, the first revised Report, for 1994–6, was expanded to cover (as best it could, for the data were still poor) the part played by the mothers' social circumstances (Figure 13.3). Many women whose deaths had been described in the earlier reports also had coexisting medical and mental health conditions, and it had been noticed that a significant number had been obese. The new-style Report provided more in-depth

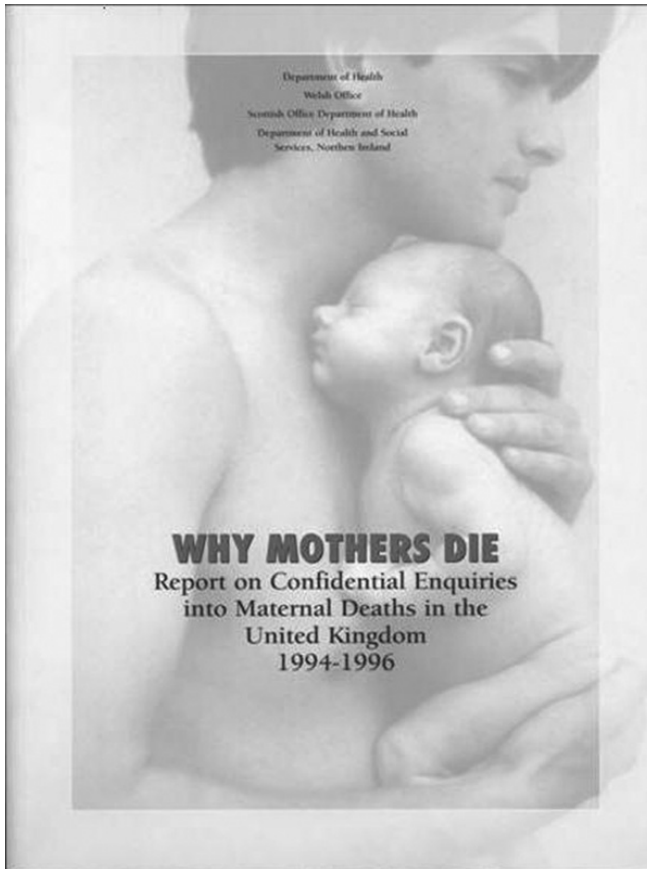


Figure 13.3 The CEMD Report for 1994–6

analysis of these and other such factors, and findings in these areas have become essential reading in successive publications.

The Report's presentation also changed. Gone were the uninviting covers of the past and in came an arresting yet simple title – *Why Mothers Die* – and pictures to engage readers' attention. In subsequent editions the name was changed again to *Saving Mothers Lives*, to signal that the purpose was not just to list the numbers and types of deaths, but also to learn lessons and stimulate improvement of care. By 2016–18 it had become *Saving Lives, Improving Mothers' Care*.

But *Why Mothers Die* represented more than a change in name and an extension of scope. It was also a marked change in philosophy, from an outdated medical model to one that recognised women as individuals who had died before their time. They were no longer described as numbers, people or cases, and the statistics became humanised; they became women and mothers. The assessors then went 'beyond the numbers', which was the name of the seminal WHO programme that arose from this enquiry. It recognised that for each dying mother there was a story to be told, that those stories held clues as why they had died, and that these in turn could indicate what could be done to improve future outcomes.

'Ignorant or self-neglectful mothers'

One regrettable feature of the early Reports was a tendency to blame the mother for her death. Failures to seek antenatal care or to comply with treatment were commonly cited. This was an easy out for health professionals who wished to avoid scrutiny, and their state of denial prevented both individual learning and wider improvements in clinical standards. In one early Report, in the 1950s, women were blamed for more than a quarter of the 406 deaths which were considered avoidable and 'only a few of these uncooperative patients were of low or disordered mentality'.

But while women themselves were often blamed because of 'their refusal or neglect to follow medical advice or to seek such advice', there was a growing recognition that for many women their social circumstances were such that seeking maternity care was low on their list of priorities. To this end the Report also says: 'some degree of responsibility rests with the doctors and midwives to gain the confidence of ignorant or self-neglectful mothers, to study their problems and to help them despite themselves'.

From 1994 onwards, instead of treating mothers as in some way complicit, the focus changed to trying to understand the barriers to care each woman

faced. New questions in the assessment included: 'What could have been done differently to help this mother?' 'What could professionals, health service managers and policy planners have done better?' 'What can be done to meet their needs in future?'

Accessing and keeping in touch with care

As today, over the past years of the Reports many of the mothers who died were vulnerable and lived with multiple and complex problems – what the latest Report for 2016–18 refers to as 'a constellation of systemic biases (Figure 13.4) (see Chapter 14). These often made it difficult for them to seek or maintain contact with maternity or other services.

In the 2006–8 CEMD Report, 44% of substance-abusing women or those known to child protection services did not register early enough in pregnancy or regularly failed to attend for antenatal care. This was also the case for 33% of the mothers who reported domestic abuse. A quarter of mothers from the most deprived areas also found it hard to attend. The very latest findings show that, in 2016–18, nearly 30% of the mothers who died still did not receive the recommended level of care.

Deprivation and socio-economic characteristics

Since 2004 it has been possible to link the mother's home postcode to a national deprivation score calculated from multiple indicators of deprivation, including employment, education and environmental factors. Each postcode falls into one of five deprivation categories. As expected, there is an excess risk of maternal death for mothers living in the more deprived areas. In 2003–5 the rate in the most deprived group was five times greater than in the least deprived. In 2016–18 this had dropped to a threefold excess risk, but the difference was still statistically significant.

Another indicator of social circumstances is the National Statistics Socio-Economic Classification (NS-SEC) code which recorded the occupation of the mother's partner, or in the case of a single woman, her own occupation. When first calculated in 2003–5, the rates of death for women with unemployed partners were seven times higher than for those who had a partner in employment and four times higher for unemployed single mothers compared those in work. Perhaps because of the advent of more locally accessible services, the risk seems to have dropped to two to three times higher for unemployed mothers today.

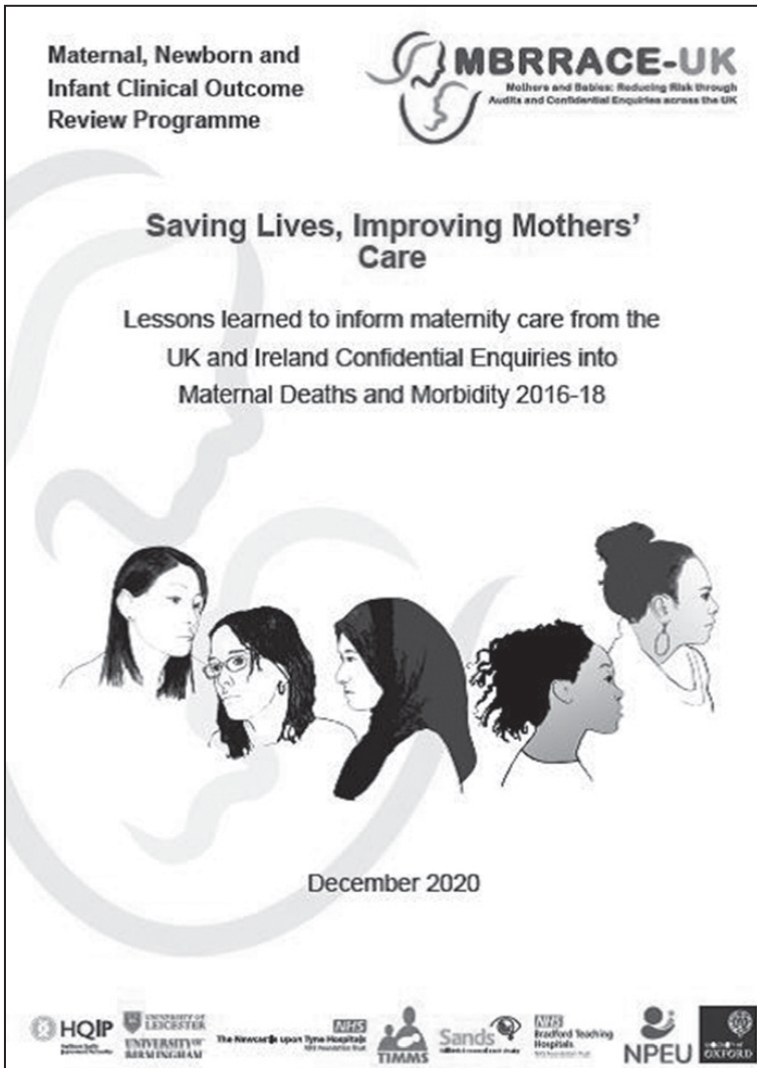


Figure 13.4 The MBRACE-UK Report for 2016–18

Ethnicity

Hard as it is to believe today, none of the great public health reports of the later twentieth century addressed differences in health outcomes by ethnicity. One explanation is the lack of data. The earlier CEMD Reports also fell short in this respect because, apart from country of birth, official and comprehensive data indicating ethnicity for England, Wales and Scotland were not routinely

collected until the 1991 census. Collection of data on ethnic groups had been planned 10 years earlier, in the 1981 census, but representatives of these groups resisted, as they considered the collection of such information discriminatory.

Information about the ethnic groups of NHS patients, including mothers, was not routinely collected until the Hospital Episode Statistics system was introduced in 1995, and even then the data varied in completeness and quality for many years.

Eventually it was possible for the newly revamped Report for 94–6 to start to identify the ethnic groups of the mothers who died. According to the best estimates at the time, Black mothers overall (a composite of women of African, Caribbean or ‘other’ Black heritage, as it was then described) were three times more likely to die than White mothers.

Gradually data collection improved. Coverage was still only 67% in the 2000–2 Report, but with judicious analysis allowing more accurate estimates of death rates by ethnic group, even larger discrepancies were revealed. Black African mothers, including substantial proportions of refugees and asylum-seeking women, were at seven times the risk of maternal death compared to White women, and Black Caribbean mothers were at three times the risk.

The difference in rates dropped from sevenfold to an average of fourfold in all successive reports. Rather than stubbornly remaining the same, however, the gap has recently widened. The latest Report, for 2016–18, revealed a death rate for Black women that was five times higher than that of White women. A twofold increase in risk was reported for women who identified as Asian or from mixed ethnic backgrounds, and this has remained remarkably consistent since data collection began (see Figure 13.5).

Among the many recent initiatives that have emerged since these findings were the development of the Race Equality Taskforce and the first Black Women’s Maternal Health Awareness Week. Guidance is still being developed by professional organisations for obstetricians, midwives and other stakeholders.

The NHS response: a raft of initiatives, policies and publications

These initiatives are very welcome but overall change has been a long time coming. The first real national policy response to the inequalities exposed in the hard-hitting CEMD Reports of the early 2000s was led by the Department of Health for England, which, in 2008, published *Maternity Matters* and the accompanying *National Service Framework* (Figure 13.6). Similar policies were developed by the other home countries. The aim was to promote ‘choice, access

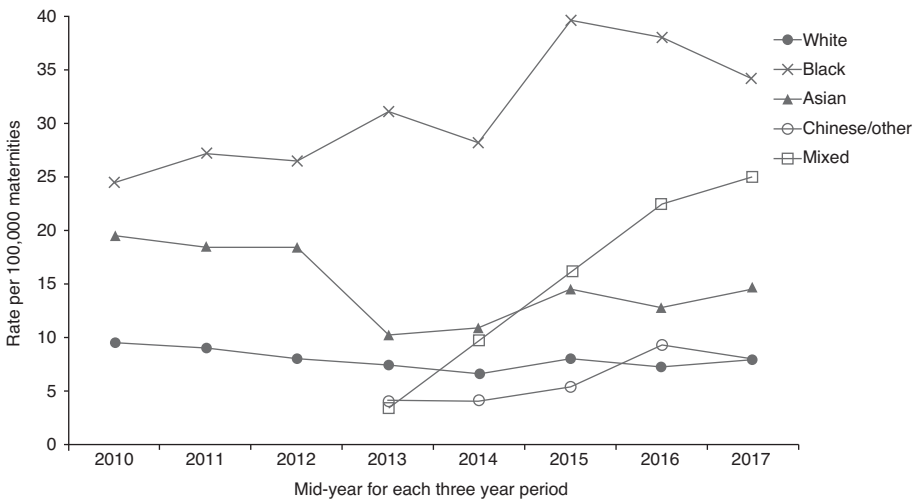


Figure 13.5 Maternal mortality rates, 2009–18, among women from ethnic groups in the UK (from *Saving Lives, Improving Mothers’ Care*, 2016–18)

and continuity of care in a safe service’ with the vision of ‘flexible services with a focus on the needs of the individual, especially those who are more vulnerable or disadvantaged’.

It also promoted individualised maternity care plans with a named midwife, one-to-one care in labour and midwife-led antenatal care in the community or by the ‘maternity team’. It was expected that care for women with complex social needs should ‘be provided in partnership with other agencies’ such as children’s services, domestic abuse teams, substance misuse services, drug and alcohol teams’.

Much in the provision of NHS maternity services changed for the better as a result of *Maternity Matters* but this appears to have had little impact on adverse maternal health outcomes. Inequalities remained among the small number of mothers who died, and research on mothers who survived severe complications of pregnancy found similar factors which give them also the same excess risk of severe complications as those who died.

In 2016 another policy drive, NHS England’s *Better Births: Five Year Forward Plan*, sought to improve maternity outcomes with by-now-familiar means: more personalised services, continuity of care with a known midwife, closer linkages with mental health services, multidisciplinary and cross-boundary working and improved quality of care (Figure 13.7). However, *Better Births* did not really address the inequalities agenda and it rather dismissed maternal

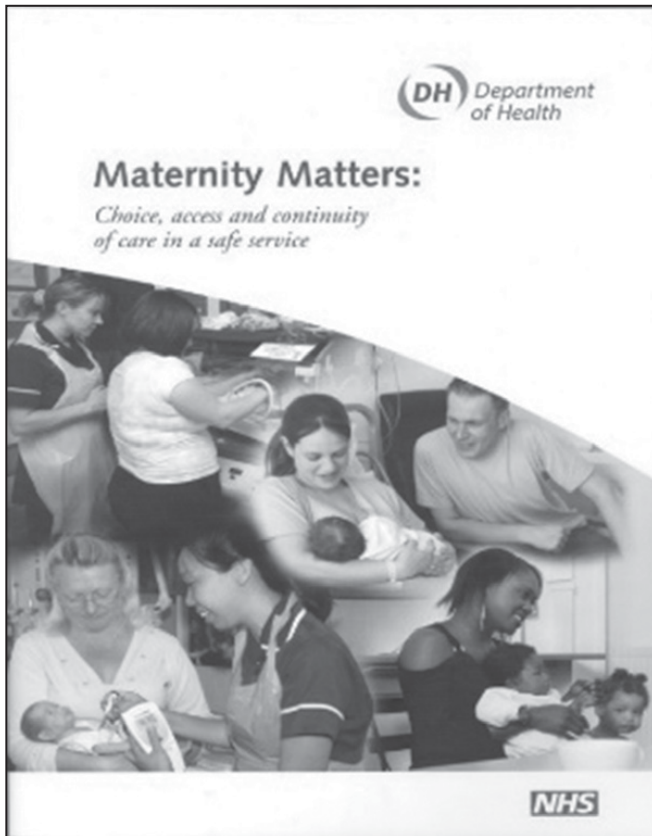


Figure 13.6 2008: The national framework for maternity services promoted the local delivery of high-quality, safe and accessible services that are women-focused and family-centred. Services should be accessible to all women and be designed to take account of their individual needs.

mortality in general because the overall rates had declined a little over the previous 10 years. It failed to acknowledge that, while the overall numbers may have fallen, the inequities between those mothers who died had not.

Better Births was rapidly followed by its implementation plan, the *Maternity Transformation Programme*. Among other things, services were encouraged 'to engage better with diverse communities'. Even more recently the stark findings of the 2016–18 *Saving Lives* report resulted in a target being set in the 2019 *NHS Long-Term Plan for England*: 'At least 75% of women from Black and ethnic minority communities and those from the most deprived groups should have continuity of care from their midwife throughout pregnancy' (Figure 13.8).



Figure 13.7 2016: *Better Births*. Our vision for maternity services across England is for them to become safer, more personalised, kinder, professional and more 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 centred around their individual needs and circumstances.

The *Better Births* report sets an ambitious target to halve deaths among pregnant women by 50% by 2025. It also seeks to halve stillbirths and deaths in newborn babies, whose own outcomes are greatly affected by their mothers' underlying health status. While these objectives are laudable, they are laughable. They demonstrate the disconnect between lofty policy declarations and the reality on the ground.

They fail to address or even recognise the abundance of evidence reviewed briefly here, and available in far more breadth and depth elsewhere, that maternal health and well-being are not uniquely dependent on the health services but are severely compromised by the multitude of long-standing underlying factors that cannot be turned off like a switch.

Deprivation, vulnerability and ethnicity aside, successive generations of women will need support to take control over their lives so they value

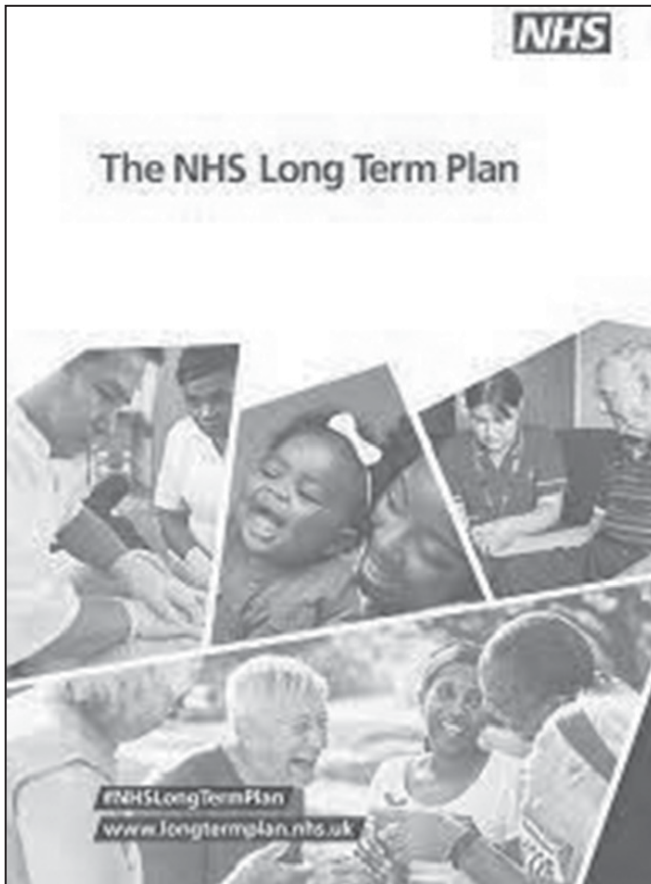


Figure 13.8 2019: *NHS Long-Term Plan for England*. The objective is that, by 2024, 75% of women from Black and minority ethnic communities and a similar percentage of women from the most deprived groups will receive continuity of care from their midwife throughout pregnancy, labour and the postnatal period. The aim is to reduce the disparities in maternal and perinatal mortality.

themselves more by becoming physically and mentally healthier. Addressing these wider factors effectively – and to the extent suggested by these impossible targets – lies far beyond the scope of health systems alone.

Conclusions

Since the beginning of the discussions about inequity and vulnerability in the 1994–6 Report, and despite the many policy initiatives, reforms, reports, working groups and focus discussions, little seems to have changed. In fact the

challenges seem even greater and disparities and gaps are widening. To bring this message home all one needs to do is consider the latest figures for 2016–18. They show that 90% of the 510 mothers who died during pregnancy or up to one year after birth were, in some measure, socially vulnerable. And three-quarters of them had pre-existing medical or mental health conditions.

Such findings are not new. In the 1930s Sir Henry Brackenbury, a distinguished doctor of the day, when commenting on the high maternal death rate, presciently said: 'I cannot help suspecting that, however important administrative and clinical factors may be, the main explanation may yet be found in those biological, physical, dietetic, sociological and even psychological factors which so far appear to have received insufficient attention.' Surely the same must be said 90 years later.